

BPSD · Dementia Care And Behavioral Symptoms

BPSD means behavior and mood changes in dementia — agitation, aggression, hallucinations, wandering, sadness, apathy, sleep problems. Always look for a fixable trigger (pain, infection, constipation, full bladder, wrong place, scary moment) before using medicine. Non-drug fixes come first.

THE ONE-LINE TRUTH

Behavior and mood problems in dementia are usually the body's way of saying something physical is wrong — pain, infection, constipation, full bladder, scary place, or bad medicine — not just 'the brain getting worse.'

The chain — how it unfolds

1. Dementia kills brain cells and depletes acetylcholine (the messenger for memory and attention, made by cells in the basal forebrain), dopamine (the messenger for movement and reward, made by the substantia nigra and ventral tegmental area), and serotonin (the messenger that steadies mood and sleep, made by the raphe nuclei in the brainstem). The brain loses its map of reality, its impulse control, and its ability to turn feelings into words. — why: Without these messengers, the frontal lobes (the brakes at the front of the brain) and the limbic system (the emotion center deep inside, including the amygdala — the alarm — and hippocampus — the memory recorder) fail. The brain can no longer interpret what is real, what is safe, or how to say 'I hurt' or 'I'm scared' in language. Every uncomfortable feeling — pain, fear, loneliness, hunger — has no outlet except behavior.

2. Something physical breaks on top of the dementia: pain (arthritis, constipation, pressure ulcer), infection (urinary tract infection is the most common — bacteria in the bladder send inflammatory signals that scramble the brain; also pneumonia or skin infection), constipation (hard stool stuck in the colon pressing on nerves), urinary retention (bladder stretched painfully full), dehydration, new medicine (anticholinergics like diphenhydramine block acetylcholine further; benzodiazepines like lorazepam sedate and confuse; opioids cloud thinking), or wrong environment (loud, bright, unfamiliar, scary). — why: The dementia brain cannot interpret or express the new problem in words. Pain is felt but cannot be named, so it leaks out as agitation, pacing, yelling, or hitting. Infection scrambles an already-damaged brain further by releasing inflammatory chemicals (cytokines) that disrupt neurotransmitter balance, causing hallucinations and delirium. Constipation or a full bladder creates physical discomfort the person cannot locate or describe, so they wander, resist care, or lash out. The body is screaming but has no voice.
3. The body sounds the only alarm it has left: agitation (pacing, restlessness, cannot sit still), aggression (hitting, yelling, resisting care), hallucinations (seeing or hearing things that are not there, often due to Lewy body dementia or infection), delusions (false beliefs like 'someone is stealing from me' or 'this is not my home'), wandering (walking aimlessly or trying to leave, searching for something safe or familiar), sundowning (worse confusion and agitation in late afternoon and evening when light fades and fatigue peaks), depression (sadness, crying, withdrawal), apathy (no interest, no movement, no eating, staring blankly), sleep problems (up all night, asleep all day because the suprachiasmatic nucleus — the brain's clock in the hypothalamus — cannot keep time without strong light cues). — why: These behaviors are not random and not 'just the dementia getting worse.' They are the brain's emergency signal that something fixable is wrong. Agitation means 'I am in pain or scared or confused and I cannot tell you in words.' Wandering means 'I am looking for something safe or familiar because this place feels dangerous.' Hallucinations mean 'my brain cannot tell real from unreal anymore, and infection or a new drug is making it worse by disrupting the little acetylcholine or dopamine I have left.' Apathy means 'I am so overwhelmed or depressed or in pain that I have shut down completely because engaging with the world takes more brain power than I have.'

4. If the trigger is not found and fixed, the behavior escalates. The person refuses all care, stops eating and drinking, becomes combative (hitting caregivers or pulling out IV lines), falls and breaks a hip, or the caregiver gets hurt or burned out and the person is sent to the emergency room or nursing home in crisis. — why: Uncontrolled agitation leads to physical restraint (being tied down, which causes more fear and delirium) or antipsychotic drugs (risperidone, quetiapine, haloperidol), both of which raise the risk of falls (from sedation and muscle stiffness), aspiration pneumonia (from sedation reducing the cough reflex so food or liquid goes into the lungs), stroke (antipsychotics raise stroke risk 1.5–2 times in dementia per FDA black-box warning), and death (antipsychotics raise mortality 1.6–1.7 times). The person spirals deeper into confusion, loses more function, and the window to bring them back closes.
5. If the trigger IS found and fixed — treat the urinary tract infection with antibiotics (trimethoprim-sulfamethoxazole or nitrofurantoin per IDSA guidelines), give scheduled acetaminophen (650–1000 mg every 6–8 hours) for arthritis pain or pressure ulcer pain, help the person use the toilet every 2 hours to empty the bladder and prevent retention, stop the new sedating medicine or anticholinergic, move them to a quieter room with softer light and familiar faces and objects, offer a snack and water because hunger and thirst feel like anxiety in a dementia brain — the behavior often calms down within hours to days, without any psychiatric drug. — why: The brain was sounding an alarm because something was broken. Fix the break and the alarm stops. The agitation was not the disease — it was the body's last way to say 'help.' Non-drug interventions (comfort, routine, calm environment, treating pain and infection per current guidelines) work better and are safer than antipsychotics, which carry a black-box warning for stroke and death in dementia. Most BPSD episodes resolve with trigger management alone.
6. If non-drug methods fail after systematic trial and safety is at immediate risk (person is hitting others, trying to jump out of a window, pulling out critical tubes), very low-dose psychotropic medication may be needed — but always as a last resort, at the lowest dose, for the shortest time, with close monitoring and a plan to taper off as soon as safe. Prefer SSRIs (citalopram 10 mg or sertraline 25 mg daily) for anxiety-driven agitation or depression. Use antipsychotics (risperidone 0.25–0.5 mg or quetiapine 12.5–25 mg) only for severe psychosis or aggression, and document clearly why all other options failed. — why: Antipsychotics (risperidone, quetiapine, olanzapine, haloperidol) raise stroke risk and death risk in dementia patients per FDA black-box warning and multiple large trials. They should only be used when the person is in immediate danger of harming themselves or others, and only after every other option has been tried and documented as failing. The American Geriatrics Society Beers Criteria list antipsychotics as potentially inappropriate in dementia unless severe psychosis or aggression with harm risk.

7. The crash points to watch for and prevent: fall with hip fracture (from antipsychotic-induced sedation, muscle stiffness, or postural drop in blood pressure), aspiration pneumonia (from oversedation reducing the ability to cough and protect the airway so food or saliva goes into the lungs and causes infection), pressure ulcers (from lying still too long because of sedation — the skin over the tailbone, heels, or hips breaks down from lack of blood flow), stroke or sudden death (from antipsychotic disrupting heart rhythm or raising clot risk), or caregiver injury or burnout forcing emergency placement in a nursing home. — why: Once any of these happens, the person loses more function, independence, and comfort. A hip fracture often means never walking again. Aspiration pneumonia can be fatal. Pressure ulcers are painful and hard to heal. Stroke steals more brain cells. Caregiver burnout breaks the last safe anchor. The goal is to catch the spiral early — find and fix triggers, support caregivers with respite and education, keep the person safe and engaged — so they can stay comfortable and connected to family for as long as possible, without the harms that come from drugs or restraints.
8. The final teaching: behavior IS communication. Every agitation, hallucination, refusal, or shutdown is the dementia brain trying to say something it can no longer put into words. Your job is to listen with your eyes, your hands, and your detective skills — not with a prescription pad. Ask: Is this person in pain? Do they have an infection? Are they constipated? Do they need the bathroom? Are they hungry, thirsty, too hot, too cold? Is the room too loud or too bright? Is there a new medicine confusing them? Is it late afternoon and they are exhausted (sundowning)? Fix the trigger and the behavior usually calms. — why: The safest and most effective treatment for BPSD is often the simplest: a calm voice, a warm room, a familiar face, fixing pain with scheduled acetaminophen, treating infection with antibiotics, helping someone to the bathroom every 2 hours, offering a snack and water, reducing noise and harsh light, and giving caregivers the support and education they need to stay steady. Medicine is the last step, not the first. Current guidelines (APA, AGS, Cochrane reviews) all emphasize non-pharmacologic interventions as first-line because they work as well as or better than drugs, with none of the risks.

Spot it — what you see, and why

- Agitation or aggression (hitting, yelling, pacing): The damaged hippocampus and frontal cortex (the memory and planning centers) cannot process what is happening around the person or inside their body—like pain, hunger, or needing the bathroom—so the amygdala (the brain's alarm center) takes over and the person reacts with anger, shouting, or restless movements instead of words.
- Repeated questions or actions: The hippocampus (the brain's recording center for new memories) is dying, so the person forgets they already asked or did something seconds or minutes ago and feels the need to ask or do it again.

- Wandering or trying to leave: Damage to the parietal lobe (the part that builds a map of where you are) and the hippocampus makes the person feel lost or confused about where they are, or they may be searching for someone or a place familiar from long ago that feels more real than the present.
- Resisting care (pushing away help with bathing, dressing, or eating): The person may not recognize the caregiver because the fusiform gyrus (the brain's face-recognition area) is damaged, or the prefrontal cortex (the part that makes sense of social situations) cannot understand that the touch is help rather than threat, so the person feels scared, embarrassed, or attacked.
- Sundowning (confusion and restlessness that gets worse in late afternoon or evening): Dementia destroys cells in the suprachiasmatic nucleus (the brain's master clock in the hypothalamus), and fatigue plus fading daylight make it even harder for the damaged brain to process sights and sounds, so confusion and fear spike as evening arrives.
- Hallucinations or delusions (seeing things that are not there, or believing something false): Dying neurons in the visual cortex (the seeing center) and the temporal lobe (the meaning center) send scrambled signals, so the person sees, hears, or believes things that do not match reality—common in Lewy body dementia and late-stage Alzheimer disease.

Red flags — act now

- Sudden violent behavior that puts the person or others at immediate risk of serious harm (choking, using weapons, severe hitting)
- Refusal to eat or drink for more than twenty-four hours, which can quickly lead to dangerous dehydration, electrolyte imbalance, or malnutrition
- New confusion or behavior change that happens very quickly (within hours to one day)—may signal delirium from infection (urinary tract infection, pneumonia), stroke, medication toxicity, or metabolic crisis rather than dementia progression alone
- Wandering outside in extreme weather, into traffic, or into unsafe areas, risking hypothermia, heat stroke, injury, or death
- Complete refusal of all medications, including those for heart disease, diabetes, or seizures, creating immediate medical danger

Treat it — in this order

1. Identify and treat the medical cause: assess and treat pain (acetaminophen, gentle repositioning), treat urinary tract infection (antibiotics guided by culture), relieve constipation or urinary retention (bowel regimen, catheter if needed), stop or reduce harmful medications. → Fixing the upstream problem—pain, infection, full bladder or bowel, medication toxicity—removes the reason the body is sending distress signals. Once the actual problem is gone, agitation and aggression often disappear because the person feels better and the brain is no longer overwhelmed.
2. Non-drug strategies first: validation (acknowledge feelings, do not argue or correct), redirection (gently change the topic or activity), music therapy, light exercise, familiar objects (photos, favorite blanket), consistent daily routine, calm caregiver presence, bright light during the day, quiet and dim light at night. → These strategies work with the parts of the dementia brain that still process comfort, safety, and familiarity. They lower the sense of threat and confusion, so agitation and wandering decrease without adding medications. Guidelines (AGS, APA) recommend non-drug approaches as first-line for behavioral and psychological symptoms of dementia.
3. SSRI antidepressant—sertraline 25–50 mg daily, or citalopram 10–20 mg daily—if depression or anxiety is present alongside the behavior problems. → Depression is common in dementia and makes behavior worse. SSRIs increase serotonin (a brain messenger that steadies mood and sleep) in brain circuits that control emotion, which reduces sadness, anxiety, and the emotional outbursts that come from feeling hopeless or frightened. Studies show modest benefit for agitation when depression coexists (Cochrane, APA guidelines).
4. Continue or start cholinesterase inhibitor (donepezil 5–10 mg daily) or memantine (10 mg twice daily) if not already prescribed, for the underlying dementia. → These medications slow the loss of thinking and memory pathways in Alzheimer dementia. Cholinesterase inhibitors (donepezil) boost acetylcholine (a brain messenger that helps memory and attention). Memantine blocks excess glutamate (a brain signal that, when too strong, damages nerve cells). A brain that is slightly less confused is less frightened and overwhelmed, so behavior problems may improve modestly. Evidence is mixed for behavioral symptoms specifically, but they treat the dementia itself (AAN, AGS guidelines).
5. Low-dose antipsychotic—risperidone 0.25–1 mg daily, or aripiprazole 2–5 mg daily—ONLY if the person is in immediate danger (severe aggression, hitting, risk of harm) and ONLY after trying everything else and ONLY for the shortest time possible. Discuss the FDA black-box warning (increased stroke and death risk in elderly with dementia) with the family first. → Antipsychotics block dopamine (a brain messenger that drives movement and emotion) in brain areas that drive aggression and hallucinations, which can stop dangerous behavior quickly. They are a last resort when safety is at immediate risk (APA, AGS guidelines).

Your top priorities at the bedside

1. Ensure immediate safety by removing objects that could be used as weapons, staying within arm's reach if the person is agitated, and calling for help if violence escalates. — why: The first priority is preventing physical harm to the patient and staff; dementia impairs judgment and impulse control, so the person may not recognize danger or consequences, and injury can happen in seconds.
2. Assess for and treat pain using a pain scale for people who cannot speak (PAINAD tool: watch for facial grimacing, guarding, resisting movement, breathing changes, and consolability) and give acetaminophen as ordered. — why: Pain is the most common reversible cause of agitation and aggression in dementia; untreated pain raises stress hormones like cortisol and activates the fight-or-flight response, making behavior worse until the pain is controlled.
3. Check for full bladder by palpating (gently pressing) the lower abdomen for a firm round mass above the pubic bone, and measure urine output; if retention is found, notify the provider for catheter order. — why: A bladder stretched beyond five hundred milliliters sends pain signals to the brain and triggers the sympathetic nervous system (stress response), causing extreme discomfort and combative behavior that resolves within minutes once the bladder is emptied.