

7 steps to managing difficult dementia behaviors -- without medication A Surviving Alzheimer's Cheatsheet

For repetition, agitation, aggression, hallucinations, delusions, pacing, rummaging, ...and many more

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A cardinal rule of dementia caregiving:

Don't reason with the person. Look for the reason why they're acting that way.

Use the "Why-This, Try-This" approach:

WHY THIS? Almost all dementia behavior has meaning. It's a reaction to a set of circumstances expressing something that the person may be otherwise unable to convey

TRY THIS! Build off that insight to try different ways of shifting the behavior to something less intense, more appropriate, or more positive

Follow these 7 steps to a better response:

- 1. REASSURE the person
- 2. REVIEW the possible causes
- 3. REMOVE any triggers
- 4. REDIRECT behavior or attention
- 5. RESTORE yourself
- 6. REVIEW what happened
- 7. REACH OUT for more help

STEP 1. REASSURE the person

- Put the person with dementia's feelings first. He or she cannot change; YOU have to change, or you have to change the immediate environment.
- Collect yourself (no matter how irritated you are). People with dementia are sensitive to others' moods and will pick yours up and mirror it. So take a deep breath. Count to 3. Or do a silent scream in the bathroom. Remind yourself, "It's not him/her. It's the dementia!"
- Avoid making the mistake of assuming they'll forget your angry moment. Although it's true that
 people with dementia tend to quickly forget what was said, the emotional impact of an
 encounter (negative OR positive) lasts much longer!

o **Do**:

- Approach slowly and from the front. You're less apt to startle, confuse, or provoke.
- Play back the person's emotions and ask questions: "You sound upset." "You look sad.
 Can I help?" "I know this bothers you. Let's see what I can do."
- Try developing a go-to mantra for soothing: "I'm here." "Everything's OK." "Not to worry, love."
- Make your body language match your words. Avoid sighing or rolling your eyes. Smile, nod, use a friendly tone, relax your posture. Unspoken factors convey more than half of any message. Try touching an arm or shoulder.

O Don't:

- o Say things like "Calm down!" This has the opposite effect -- it raises anxiety.
- o Ask, "What's wrong?" When someone doesn't know or can't answer, it's irritating.
- Try to reason with the person (no matter how tempting). Logic and argument will not work. Period.

STEP 2. REVIEW the possible causes

Odd behavior is seldom "on purpose." Search for clues:

- Consider the timing. Is this a change that's come on over recent hours or perhaps days? Suspect
 delirium due to illness or something immediate in the situation. A change in medications could
 also be the culprit.
- o **Ask yourself if there's a pattern to when or where the problem seems to happen.** Could something about the noise or people present then (or there) be bothersome? Do problems escalate in late afternoon? Changes in light, shadows, and fatigue then may cause an uptick in restless behavior known as *sundowning* (as in, when the sun goes down).
- Make a mental sweep of anything new or different that might have set the stage. A change in routine? Houseguests? A new prescription? A hot day? A different aide? Symptoms of illness?
- o **Consider possible unmet needs.** At the root of challenging behaviors is often:
 - A basic physical need. Could a late or forgotten meal be making the person "hangry"? Might an incontinence product need changing? Is sleep poor?
 - *Pain*. Watch body language, like wincing, moaning, or holding/rubbing a body part. Are there related symptoms, like fever or sores?
 - **Another physical cause**. Constipation and mild dehydration often influence dementia behavior.
 - Overstimulation. Is it a busy public space? A lot of background noise? One too many errands?
 - *Understimulation/boredom*. Might the person not have enough to do or be looking for an outlet? Is he sleeping too much or not getting enough fresh air or exercise?
 - *Frustration*. Has an activity become too difficult? Do you sense a building struggle to keep up?
 - **Feeling unsafe**. Is there something about the situation causing uneasiness, anxiety, or fear, like strangers or crowds? Sounds or sights that are perceived as threats?

Ask the person questions that might give you added useful info (and that show you're on their side). Avoid "Why?" ("Why are you doing that?")

Better: Use the other W questions, riffing off what they're doing or saying to you:

- "WHO are you looking for?"
- "WHAT can I help you find?"
- "WHERE do you need to go?"
- "WHAT will you do there?"

Or use these four terrific words: "Tell me about it."

STEP 3. REMOVE any triggers

By eliminating what sets off a behavior, you might be able to end it. Types of triggers:

- *Visual triggers.* Keys or a coat near the door can trigger a wanderer. A clock may lead to repeat questions about time. Move the trigger, or relocate the person.
- Activity triggers. Something happens (saying goodbye) that trips a response (repeating "I want to go home") so try to end that cue (skip the big goodbye scene). The sound of water running can remind of a frightening bathing experience. (Play music to mask the sound.)
- o *Misperception triggers.* If shadows look like "robbers," close curtains. If a mirror reflection is thought to be an upsetting stranger, cover or remove the mirror.
- Discomfort triggers. Address the source: food for hunger, a fan if it's hot, soft clothes if itchy
 ones are removed, a different seat if there's glare, and so on.
- o **Frustration triggers.** Avoid resisting a delusion or hallucination; calmly ask questions about it to help the person feel understood. "Therapeutic fibbing" (going along) is usually kindest and calming. If an activity is beyond ability, offer support or casually end it. Rest is key when just trying to keep it together overwhelms.

STEP 4. REDIRECT behavior or attention

Use your words or actins to shift the person's energy or focus away from the stressful thing and toward calm. Some ways to do this:

- o Introduce a diversion without belaboring the reason for it: "Hey, I have an idea, let's...." "Look at the funny birds at the birdfeeder...." "I need your help with...."
- Offer a choice of two things the person likes to do: "Would you like to have your ice cream now or go and rock on the porch with me?" For someone who has difficulty making choices, express it as a yes/no question: "Would you like some ice cream?"
- Lead the person to a change in scenery. It might be a different chair, another room, or from inside to outdoors. You can't physically force them along, which only creates more stress. Instead, try using body language. Offer your hand. "Where are we going?" the person may ask. "It's a surprise," you say. That word alone can be diverting—everyone's intrigued by a surprise. (The "surprise" can be as simple as a snack, a look at the clouds, or a YouTube video.)
- o **Introduce an entirely different kind of activity.** Sensory experiences, like gardening or helping to prepare food, create positive emotional associations.
- Use bridge phrases to change the topic of conversation. Certain transitional words "build a bridge" to a new direction—away from the thought or image that got the person stuck. "I'm

sorry your sunglasses are missing. *That reminds me of* the time you wore them whale-watching." Also good: "Yes, and what I'd really like to know is...." "I've also heard that...."

Steer toward a cheerful past. Some people are soothed by comfort objects, like a stuffed animal
to pet, a doll to hold, a toolbox to arrange—often things linked with positive memories of their
past. You have to use trial and error to see what's effective but respectful in an individual case.
Music, sports games, or talk of weddings (any wedding!) are often popular topics for revisiting.

STEP 5. RESTORE yourself

When an episode is over, give yourself a moment. Your calm matters, too.

- o Release some stress. Take a few deep breaths. Text a friend. Scrawl in a journal.
- Go easy on yourself going forward. Self-kindness isn't optional. It gives you the patience and resilience that caregiving requires. What helps:
 - MORE hands-on help. Explore paid and volunteer sources; start with your local Area Agency on Aging. Get help with household tasks like outsourcing lawn care, having groceries delivered.
 - *MORE downtime*. Even 15 minutes a day recharges. Try hired elder companions as well as family or friends to spell you.
 - MORE stress outlets. Among the best: sleep, exercise, social time, and safe places to vent and share your frustrations (a journal, a friend, a virtual community for caregivers, or a local support group).
- Remind yourself, "I'm only human." We all say and do unhelpful things. Celebrate small victories. Aim for B+ care, not A+++.

STEP 6. REVIEW what happened

To prevent future incidents or head them off faster:

- Track what seemed to be going on at the time and what worked. Just jot down the time of day and what happened. (You think you'll remember but you won't.)
- o **Engage the power of routine.** The more patterned the day, the less off-kilter someone with dementia, especially meals and sleep. Include time outside or near a bright window.
- Weave physical and mental stimulation into the person with dementia's schedule each day.
 Modest exercise (even walking or stretching), social time, and having things to do boost mood and improve sleep, which helps lower behaviors rooted in anxiety, depression, and fear.

STEP 7. REACH OUT for help

There's no need to try to figure this out all alone. Whether you're feeling completely stumped or simply could use a little encouragement, reach out and find reinforcements to help you address persistent behaviors.

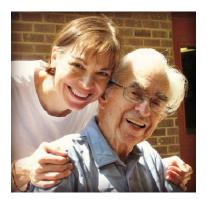
 For help with non-drug approaches. Behavior modifications are always the first resort because they're safest and improve care relationships in the long run. From others, you might pick up a tip or strategy that you hadn't considered.

Good places to find this kind of hands-on, situation-specific care advice include:

- Virtual communities for dementia caregivers
- Local Alzheimer's (or other dementia) support groups
- Consultations with dementia-care experts, e.g. geriatric care managers
- A course or workshop
- Books about dementia care
- For medical assistance. Talk to the person's doctor. Though often risky, medications can sometimes help with some behaviors. It's especially important to quickly get medical help if:
 - You feel unsafe due to violent, aggressive, or unpredictable behavior
 - The person's sleep is disrupting yours

For an in-depth guide to handling over 50 specific behaviors, see: <u>SURVIVING ALZHEIMER'S: Practical Tips and Soul-Saving Wisdom for Caregivers</u>.

Includes care insights from leading dementia experts and tough topics no one likes to talk about -- from stress, guilt, and resentment to end-of-life care.



Family-life consultant <u>Paula Spencer Scott</u> is the author of a dozen other books on health and family, including *Like Mother, Like Daughter*. Active in caregiver education, she's written curriculum for Weill-Cornell Medicine's Alzheimer's Universe, created scripts for caregiving advocate Leeza Gibbons, and developed the original Caring.com Alzheimer's channel, and often speaks on these topics. A longtime *Woman's Day* columnist and former contributing editor to WebMD, Caring, and Parenting, as well as a Gerontological Society of America journalist fellow, her work appears in *Parade, AARP, Next Avenue*, and elsewhere. Five close family members have had dementia.

Find out more at <u>SurvivingAlz.com</u> or the *Surviving Alzheimer's Together* Facebook group.