

Understanding the Behavior of Individuals Living with Dementia: A Quick Guide

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Dementia commonly causes impairments such as short-term memory loss, having difficulty recognizing one's surroundings, trouble making and carrying out plans, and expressing one's needs or feelings using words. As this condition progresses, individuals may eventually become totally dependent on others for all aspects of care. In the earliest stages of dementia, individuals may seek care in assisted living communities because of 'forgetfulness.' This memory loss is often confused with normal aging. The condition typically worsens slowly over time, however. In addition, brain function may become suddenly worse as a side effect of medications, even over the counter drugs. People who are confused or have memory problems do not usually know that they have a problem and therefore do not ask for help. They can't remember to.

Certain behaviors and situations may be especially challenging for caregivers or other residents of a community. There are several key points to remember, when evaluating these situations and helping individuals in need.

1. Behavior is communication, not a disease. Our challenge and our obligation is to figure out what they are telling us.
2. These behaviors, however upsetting, are not intentional. They can't help it. It is not their fault. Put yourself in their shoes: What are they looking for or reacting to?
3. Just because someone is behaving in ways we don't want them to does not mean that they are sick and need medicine. Medicines to make people behave don't make them behave. They cause more confusion which often makes the problem worse and they have serious risks in older people including increased risk of death as a side effect.
4. The most challenging behaviors, especially problems encountered when trying to provide personal care, are a natural response to a perceived threat. These behaviors are not planned. They are a reflexive response. These are the same exact behaviors that you would do if you felt threatened or attacked (like if a stranger started touching you or tried to undress you).
5. All of the behaviors you may encounter when caring for someone who is living with dementia are the exact same normal behaviors you have seen in young children throughout your life. If you are a parent or have ever been a babysitter, remember what you did to help the child in that same situation.
6. Challenging behaviors in care settings represent a conflict between the individual and the environment. Confused people and people with memory problems cannot understand or remember the rules of the house, and therefore can't follow them.
7. Our task is to find out what their behavior is telling us. What feeling are they expressing? What do they want? Is there an unmet need?
8. What is our behavior telling them? If you are in a hurry or standing over someone, if you are doing something they don't understand, they may become upset or frightened and respond in a way that you don't want. Slow down, sit down, speak in a slow, calm reassuring voice. Explain what you are trying to do before you do it. One step at a time. It's all in your approach.
9. If you are finding it difficult to provide care to a resident, stop. Walk away and try again later. Ask for help from others. How do they approach the task or situation? What has worked for them? What hasn't?

Some examples of situations you may encounter:

'Wandering'

Wandering is moving about in an apparently aimless manner or going somewhere someone else doesn't want them to. Most often it is quite normal, but unacceptable. Like entering the wrong apartment (Have you ever done that? If so, why?). Or attempting to open a door or leave the building (usually where there is a big red exit sign). What might this behavior mean? It might simply mean a desire to walk or move. Or a need to find a bathroom. It may be that someone is lost or can't remember where their apartment is. It may be in response to a big red exit sign or seeing other people going out the front door. Stop signs on doors or stairwells, large door signs and photos on an apartment door may 'steer' people away from hazards and towards where it is they are trying to get to.

We need to ask what they are looking for or where they are trying to go and help them. We may need to anticipate such a need and plan to help them before they wander. (Like assisting to the bathroom after meals). Saying they cannot or are not allowed to ("reorientation") usually doesn't work and often makes the situation worse. Offering to help, perhaps distracting them with an activity or some other task or activity first (i.e., if they are trying to leave the building) may work, as they often forget what it was, they were trying to do that you didn't want them to do)

'Agitation'

This is not a disease. It is a term that is used mostly in health care settings that simply means that *someone looks upset*. It is caused by many many things. (How many different things or situations in your life have made you upset?) It is better to communicate and document that someone looks upset and find out what is upsetting them or what they are feeling. The term agitation often results in unnecessary and unhelpful medications when communicated to a doctor or other prescriber of medicines.

Residents who appear upset are often responding to something happening in their world right now. Are they upset because someone is undressing them to provide incontinence care or bathing? They may not understand that and be afraid instead. Or cold. They could be in pain, hungry, lost, lonely, missing a loved one. Tell them they seem upset and ask them why. Provide reassurance and comfort. If they are upset with you or what you are doing, stop. IF you keep going it often makes it worse.

Often '**agitation**' results in '**resisting care**' or is misperceived as '**aggression**'. These terms are unhelpful, and often represent misunderstanding of situations by caregivers resulting in incorrect responses. When someone is 'resisting care', they are telling you to stop what you are doing. They usually don't understand what you are doing or why, and it frightens them. Stop what you are doing. Walk away and try later. Seek the advice of your teammates about how they approach the same situation. 'Aggression' implies that someone is doing something on purpose and is capable of planning and remembering. People living with dementia are generally not capable of planning or remembering. They are taking defensive action instead. What is making them afraid or upset?