## Bob's LAST MARATHON Living the Alzheimer's Journey

## **TRANSCRIPT**

## Challenging Behaviors Tips and Techniques

Stefanie Bonigut: Jodi had come to a support group to get suggestions on how to address a behavioral symptom her mom with Alzheimer's was experiencing. Her mom had what Jodi called fantasies and she often wanted to act or did act on them. One example Jodi gave was her mom telling her that people had been hanging around the house and now they'd stolen her car. Her mom wanted to go tell the police. She kept trying to leave the house to go to the police office even though Jodi kept telling her the car wasn't stolen, that they had sold her car. Jodi got frustrated during the situation. She said she didn't yell at her mom, but she was definitely speaking loudly and fast and her mom had started pacing around the room. Jodi thought it would help if her mom saw the paperwork for the car sale, but while Jodi was looking for it, her mom left the house. It was dusk, and luckily a neighbor was out walking their dog and brought Jodi's mom home shortly after she left. Jodi was still upset, but her mom was fine. Jodi felt terrible about what happened, but she's so overwhelmed with taking care of her mom and working and raising her own kids. Jodi's mom used to do lots of craft projects and be physically active, but now she spends much of her day just watching TV, especially news shows. Felicia, what strategies are there for managing this situation?

Felicia Greenfield: Yes, that's a tough one. There are a lot of safety concerns here and a lot of risk factors. So let's start by talking about behaviors in terms of what's causing them. The first thing caregivers should consider is whether a person's behavior is caused by a medical problem or not. Common medical problems that can affect behavior are illness or medical conditions, medication side effects, or sensory impairments. People with memory loss cannot always effectively communicate pain or discomfort such as musculoskeletal pain, constipation, or hunger, and certain illnesses can organically impact cognition such as urinary tract infections or fevers.

Some medications can impact mood, appetite, sleep patterns, GI function, attention span, and more. And if your loved one can't see or hear properly, then their cognition will likely appear to be worse. So it's important that these conditions be adequately diagnosed and treated by your loved one's primary care doctor or by a specialist. And it's always a good idea to remember to call the doctor if there is a sudden change in your loved one's functioning or cognition.

Once medical considerations are ruled out, then we ask caregivers to become behavioral detectives. It's important to remember that most behaviors have a purpose. So if your loved one can't find the right words to describe pain or discomfort, they may yell when you're trying to get them out of bed or to take a shower. If your relative or loved one is bored but unable to choose an activity of their own, they might pace around the house and appear fidgety. There are several reasons why a behavior occurs and these may change over time and from person to person. For people with memory problems, there are at least five major causes for challenging behaviors. One is to gain attention; another is to increase sensory stimulation. They may be trying to gain access to an object or something they want. They may be trying to escape or avoid something unpleasant. Or they may be responding to an internal emotional state like fear or anxiety or a physical state like hunger or fatigue.

So how do we figure out what we're dealing with? Well, we suggest trying to use an ABC chain. A stands for antecedent, or what happens before the behavior occurs. Examples of antecedents are, maybe a demand was placed on your loved one, like "It's time to take a shower" or "Please finish eating what's on your plate." Sometimes things outside of our control can affect a person for a long period of time, like sometimes the time of day or a season can bring on the behavior. And to our last case study, problematic communication

between a caregiver and care recipient can also cause behavioral issues.

Another thing that might happen is a life transition or a major event like moving or a fall or a hospitalization. And then there are environmental factors like noises, sights, or physical space that may be bringing on some of the behaviors. And then finally, cues or triggers specific to your relative could create a particular behavior. For example, a briefcase sitting in the hall may remind your loved one that they might go to work and they may try to leave the house, or a wedding or a TV show may remind them of a deceased spouse. So in Jodi's case, her mother was watching TV before the behavior occurred. We might hypothesize that her mom was bored and understimulated. So antecedents are what's happening before the behavior, and then B in the ABC chain is the behavior or what your loved one does. In the case of Jodi's mom, this may have been a case of confabulation or weaving the news she was watching into her reality. Another behavior in this example is pacing, which is an expression of anxiety. This may have occurred in response to Jodi not believing her and Jodi's expressed frustration. Finally, the behavior of wandering or exit seeking. Jodi's mom left in search of the police for help. So those are all behaviors, things that we can observe with our senses.

And then *C* is the *consequence*. *C*, the consequence, is the reaction that occurs after the behavior, such as what you or your loved one does next or how each of you feels. Consequences are important to pay attention to because depending on how you react to a situation, you may actually increase or decrease behavior. However, a person with memory problems may have difficulty learning new information, which also means difficulty understanding action and reaction as well as right or wrong. So for example, let's say that every time your loved one refuses to shower, you take away their dessert. The next day, it's likely they won't remember that the consequence for no showering is no dessert. So in our example, Jodi tried to reason with her mom. Unfortunately, reasoning and connecting do not work.

That part of the brain is no longer functioning the way it used to. When Jodi's reasoning failed, she was left feeling sad.

The only things you as a caregiver have control over are the antecedents and the consequences, not your loved one's ultimate behavior. There may be times when you cannot alter the antecedent or the environment. For example, we can't control when it gets dark outside. During these times, changing how you react to the behavior might prevent the situation from getting worse in the moment. You also have control over how you reward your loved one's good behaviors. Your loved one may not be able to connect the reward to how they behave in the future, but providing a reward will improve both of your moods. Try to use a specific reward that you give only when a desired behavior occurs. In our example, Jodi can try to change the environment so that her mother is more stimulated and engaged and not watching the news, which may have led to her confabulation. Jodi could try securing resources available in the community that promote engagement, such as adult day programs or in-home respite.

In the era of COVID, there are many online resources available such as Memory Cafés or arts-based programs that promote social engagement. Jodi can also arrange for an occupational therapist to come to the home to modify the environment and teach Jodi activities to help keep her mother engaged. In case Jodi's environmental change did not prevent her mother's behavior, Jodi could change the consequence or her response to the behavior by avoiding the desire to reason and instead, acknowledge without agreeing or committing to something. She could validate the emotions behind her mother's words and focus on the feelings rather than the facts.

I often teach the caregivers I work with the art of loving deception or therapeutic lies. When used well, creative storytelling can help us focus on nonverbal communication such as tone, volume of voice, and

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body language. And finally, Jodi can also redirect her mother's attention.

Stefanie: I agree with you, Felicia. I think sometimes we can't figure out the emotion or what's causing the behavior. But redirection is a way to help get the person in a more contented state. Calm them down, redirect that energy.

**Katie Brandt:** Well, what a beautiful segue to a very important question that came in where the caregiver is asking, what do I answer when my mom says, "I'm scared?"

Stefanie: I would validate that emotion. "I'm sorry about that, Mom. I know you're scared." You know, talk about your own feelings: "I'm scared too," and then reassure. "We're safe together. We're here together, we'll be okay." Provide that validation of the emotion to help reassure them. And I would also then try it a little bit, move into the distraction. After you validate, reassure. Go ahead and, "Let's go get a cup of coffee, let's get a cup of tea."

**Katie:** One of our audience members said that their loved one is younger, under 60 years old, and is asking, do we have any different ideas or recommendations for activities due to the loved one's age?

Felicia: I would focus on what they like to do. So I don't think that these are age-specific activity suggestions. I think you really want to focus on what that person finds enjoyable, finds meaningful, and tailor the activity to those things. What will make them happy?

Stefanie: I also used to facilitate a young-onset Alzheimer's group, and the folks felt that adult day program populations were older than them. But a lot of times, the younger folks went in as "volunteers" and if they were physically able, they were helping the other folks in the program even though they themselves were participants. And every program that I've worked with in the San Francisco Bay Area was absolutely on

board on getting younger folks involved in that respect. So they may feel like an adult day program is not for them, but we can massage it into a program that's good for them.

Katie: Any tips for caregiver grief and depression?

Felicia: I think caregivers are experiencing ambiguous loss in anticipatory grief in their role as caregiver, and it's important to acknowledge that and find support through a support group or through an individual therapist to help you process those feelings that you're experiencing. They are normal.

Katie: You know, I think that being able to say out loud that you're having those feelings, that you need that support, can be tough sometimes with the people who love you. They want to fix it, they want to undo it. But in that support group environment, you'll have peers who understand where you're coming from. The good news is that many support groups are available online today, which makes them more accessible.

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