Agitation in Alzheimer's: A Caregiver’s Journey

**Announcer:**

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**Dr. Montano:**

This is CME on ReachMD. I’m Dr. Brendan Montano. Joining me today is Sue. Sue, walk us through your caregiver journey with your spouse and the recognition and diagnosis of agitation in Alzheimer's disease.

**Sue:**

Alzheimer's creeps into your life. It's subtle. It's sneaky. You think something's changing, but you're not necessarily sure why, because there's so much life happening around you that somebody's lack of patience or raised voice, or there's too many reasons it could be until there's only one reason, and it becomes apparent.

When I initially met my husband, I was attracted to his intellect. We had spirited discussions, philosophical discussions. We’d take Sunday afternoon drives and debate philosophical ideals. And then over time, the discussions became, how about we listen to a CD instead of our favorite music? Okay, well, that was pleasant. And you don't think that there is a reason behind the change. And then you start to notice that, gee, he's really much more impatient, and he's much more angry. In fact, that's the term. I want to put that in there, because the term professionals tend to use is agitated. No, it's not agitation, it's anger. And it registers on those of us that are around the person as anger. And even if we eventually know where it's coming from down the line, the emotional response is, I'm still being yelled at.

So people always say when you start to say your husband has dementia, they immediately come out and they say to you, ‘Oh, does he still remember who you are? Does he remember who his kids are?’ That's not what you have to worry about. It's, is he so angry that he's going to pick up his cane and use it on me and not just in the grocery store? Because my husband's anger got to the point where if he bumped into something in a grocery store, he picked up his cane and proceeded to try to beat the display. And you had to stop him physically in order for him to stop.

Other times in the grocery store, he would become so verbally abusive to me that passersby would literally come around us to protect me from him. And one woman, bless her heart, literally followed us to the other side of the store and pressed her phone number into my hand because she was so concerned. And she said, ‘You don't have to live like this.’ It's one thing to have to live like this at home, but when you are out and you're realizing that people are so concerned about the behavior that they're seeing outside the home that you're seeing 24 hours a day inside the home, then you start to think a little bit differently too.

I told you that we used to have detailed, intense, well-thought-out discussions, and those gradually changed to what I refer to as See Dick Run speak. And I gradually learned that whatever kind of confusion was going on in his head, that I couldn't initiate conversations anymore without him, for whatever reason, I still don't know, he'd get angry and I would end up being yelled at. So what happens is I stop talking until he says something, and then, if it's about the Western or whatever that was going on the TV, it was just I stopped talking.

And then he had surgery, and overnight it seemed he got worse. The anger got greater, he was weaker, and suddenly I was now a 24-hour caregiver. Now I have my own business. COVID hit us hard. I'm in the arts. And besides that, I needed two hips replaced. Well, the hips weren't going to be getting any attention at this point, because he needed the care. He needed the attention, and suddenly I was running a complete household. I'm paying all the bills. I'm in charge of everything. And so I did as much as I could, but I was only in the office for a few hours every day, and it finally got to the point where I felt like I was two people. I was Susie 24-hour caregiver, and then I was the competent businesswoman in arts management with a passion for an industry that I absolutely adore. And it actually would take me – I would have to physically take time in my car, when I left in the morning, a good 5-10 minutes to transition to be the second person.

And then it gradually got to the point where there was no time for the businesswoman. His care was all-consuming. Nobody tells you that. Nobody tells you that they're going to forget their concept of time and that he's going to get up at 2 o'clock in the morning and suddenly make himself pancakes and leave the stove on, and it's a good thing that it woke me up. And that goes on and on and on. And so then suddenly you have months with interrupted sleep, not one or two days a week; it's constant. And the anger is constant. And the yelling gets constant. And I have to get to the point where I have to know where his cane is because he reflexively now picks it up to hit what's ever bothering him. And sometimes I bother him.

I didn't want to be a 24-hour caregiver. It's not what I chose, and it finally became too much for me, and I spent 4 days in the hospital and then required outpatient help afterwards. The drain physically, emotionally, mentally is very hard. And then if you happen to have something that your own health that you have to take care of too, the world doesn't compensate for that. And so you come out of the hospital, and I came out of the hospital after two hip replacements, and I was still a 24-hour caregiver. If you're not independently wealthy, and we're not, we had to live on our Social Security during this time, just our Social Security. And then I had to figure out this care was too much, and I couldn't care for him anymore 24 hours a day. It was all-consuming. There was nothing else I could do. So I spent 6 months and hundreds of pages of paperwork so that I could get him someplace where he could hopefully thrive. And I did, and nobody ever told me that it was going to take all this on the journey to get him into a safe place where he could thrive.

One last thing that nobody told me was I'd have to relearn my own mental acuity. I'd have to rebuild my own stamina to carry out my business. And at 73, that's what I'm doing, and I'm grateful that I still can so that we each, both my husband and myself, can have lives that we both can thrive in.

**Dr. Montano:**
Sue, I can't tell you how impactful that discussion was for me personally and for our listeners I'm sure as well. It is a very important thing that you communicated as clearly as you have, the journey that you've been on and your own particular problems that you had to deal with while you're dealing with the person that you've loved for so many years. So I thank you again for sharing your journey and the pain that you've been through with this. And I think that's going to touch all of us and make us, hopefully, more aware of what you call, and I think, very appropriately, the anger, not just the agitation, but for you it's been really serious anger and even physical anger, physical abuse. So this is not the person who you started with. It's the person, but in a new mode and a different way. And this is what Alzheimer's does, unfortunately, to many of its victims. So thank you again for sharing that.

It's been a very brief but a great discussion, and our time is now up for listening. So thanks again, Sue. Hope you have a wonderful rest of your day.

**Sue:**
Thank you.

**Announcer:**
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