LeAnn

Still Here: A caregiver series

Jeff doesn't know that we're married anymore. You know, because of course when we had those conversations early on and I'd say—like I think we all do—is "promise you won't forget me," you know.

My name is LeAnn, and my husband Jeff has younger onset Alzheimer's. Jeff was officially diagnosed about 3 years ago, but he's had symptoms for 7 or 8 years.

We had met at a marketing conference and just kept in touch businesswise here and there through the years. And we happened to then reconnect again. We just hit it off.

So we started dating and as we were dating was when Jeff started feeling like something might not be right with his health and how he was feeling.

It was scary because I was falling in love with this man. And at the same time, my grandmother had had Alzheimer's and so I just had this feeling in the back of my mind. We ended up knowing that he had a diagnosis of, at that time, mild cognitive impairment. We still chose to get married and move forward.

I could have walked away a million times and I just couldn't. I just couldn't. And I felt like I was called to take care of him.

So with Jeff looking perfectly healthy in his late 50s and early 60s, but having a brain disease, it was really hard sometimes. I think about movies, and movies where it sort of glamorizes the disease. Where you'll see people that are just talking normally, maybe a little forgetful, and even their memory may come and go and then, you know, perfectly healthy—and then just lay down and pass away.

That is *not* dementia. Dementia is not remembering how to use the toilet. Dementia is not being able to swallow, you know, putting your food in your cheeks and—and chewing it for 10 or 15 minutes and having to be reminded that you need to swallow your food. It's forgetting how to walk. It's not being able to stand on your own 2 feet. And those are the things that you deal with when you get to these final stages that people just don't talk about.

I was in a pretty dark place with Jeff's disease for about a year because he was really starting to progress, and we were going through it with the anger, the toileting issues, the things that are really hard to deal with.

I went to a local education session about dementia and a gal spoke who had lost her husband. And she said, "I promised I was going to take care of my husband, but I was not going to lose myself in the process of doing so." And that resonated with me so much.

I cannot miss out on this time in the lives of my, my daughters.

I feel guilty sometimes that I'm, you know, going out and doing these things, and he can't. And it brings all the emotions too. Sometimes I'll be sitting somewhere and just start crying because he's not with me. And other

times I feel joyous because I'm getting to do something that he'd love to do, and I can still go home and tell him about it. I've just really just started to prioritize myself and I know Jeff would want that.

We definitely connect by still, you know, dancing and just turning on the music. And if it's a song that I know that he loves, I'll still wrap my arms around him and shuffle with him in the kitchen. And even though he doesn't really dance back like he used to, I can just feel when I just wrap my arms around him, just that he still loves those hugs, and that type of connection.

Still when I get into bed every night, I lay my head on his chest a little bit and things, because that's when I can really just at the end of the day say, "Here I am," with my head on his chest and he's still my husband, he's still...he's still here.