

Caregiving and Social Media

Still Here: A caregiver series

JESSICA: I didn't know anyone else that was navigating early onset Alzheimer's disease, so I didn't know what was normal.

BAILEY: Something as simple as putting locks on my cabinets, I felt weird and insecure about doing. But then I saw someone else in the community did it. I can't tell you how much stress that lifted off of my shoulders. Okay, so it's not horrible if I do this. Other people are doing it too.

JESSICA: There's something about social media that, you know, I feel like I got closer to people even though they were, you know, just through a screen and thousands of miles away. But I would say I have learned so much about dementia, helping my mom through different stages as things progressed, all through this community we have online.

JACQUELYN: People are desperately wanting to feel seen. People are desperately wanting to talk to someone who they can relate to and share stories with. People are looking for answers, because there are so few out there.

JESSICA: Sharing on social media created a community for me that I didn't that I didn't have in real life. And that's also why I started sharing so publicly on social media. I found other young black women who are caregivers.

JACQUELYN: My mom had started calling me Mom. I was filming her that day, and she was looking at that photo, and she pointed at herself, and she was like, “That's me.” And then she pointed at the baby picture of me and said, “That's my mom.” People were responding to it in a way that I just wasn't expecting at all.

BAILEY: I posted a video of me, I was talking to my dad inviting him over for dinner. Because my dad forgets he lives with me every day, so I have to invite him over to stay the night at my house every day. And I just posted that and I woke up the next morning and they had hundreds and thousands of views.

JESSICA: I found other people around the world who were navigating Alzheimer's disease with their parents. I found people who had been on the journey but were no longer on this caregiving journey. And there is something really comforting about realizing like, oh, your story's—your story is actually not unique, right? Your story is actually one of, you know, thousands.

JACQUELYN: It just continued to grow and grow and grow and grow and more people saw it and more people were like, “Oh my gosh, I care for someone too”. That's when I actually saw that there's

so many people caring for someone. And it's not just me. And, and there is a community out there and like, that's sort of how I was like, "This is bigger than I even thought."

BAILEY: Just me existing and talking about what I'm going through is enough. And that's a really good feeling. I'm very grateful for the Internet. My mom would not appreciate me saying that because she tried to keep me off the internet for so long. Changed the Wi-Fi password and everything, all the time, as a kid. Look at me now, Mom.