

Carlos

Still Here: A caregiver series

Caregiving is creative. You have to go with the flow. You have to innovate on the spot.

We were living in a household that was full of art. As far as I can remember, my dad was always creating something.

And he was diagnosed in 2015 with mild cognitive impairment.

November, December of 2016, I was fully moved back home to the childhood house I grew up in.

Back in August 2020, my dad stopped taking showers. It was heart wrenching to see the person that you love, your hero, disregard himself.

One day, I walked into his room, knocked on his door, a little bit earlier than usual. And said, “Let's go get a donut after you get into the shower.” He pops up out of bed, walks down the hallway, and heads to the shower. A simple adjustment to a morning wakeup routine worked.

And then also put notes on the bathroom mirror. Saying this is a daily routine that will help you get to 109—a lifelong goal. Just a reminder, just a little love note.

I feel like I fail a lot. Fall back 5 steps just to gain one. But I never gave up.

At any given moment, I'm 50% content and 50% depressed.

There's times where I felt completely exhausted, full of frustration. I didn't feel like getting up out of bed to support my dad.

One day I called a helpline and the person on the other end of the line says “So, how are you doing today?” I felt comfortable enough to let out my frustrations, my emotions. They suggested I attend a caregiver support group. And, I did.

I was very hesitant to walk into a caregiver support group. It was embarrassing. I felt ashamed. No one looked like me. It was mostly women. And there was an age difference. They were much older.

I sat down, listened to what was being said. I ended up giving my story at the time, and I was welcomed. I left there feeling like that was where I needed to be.

It's hard to ask for help. It's hard to be uncomfortable. It's hard to be frustrated. It's hard to be angry. It's hard to be confused. Sometimes, you cannot do it alone.

Now, I attend about 6 caregiver support groups as well as hosting one locally in my area.

My dad has Alzheimer's. But I'm not taking away from the human that he is. And today, he continues to draw despite, despite having a neurodegenerative disease.

I get to put his artwork into a gallery. I get to show the world that Alzheimer's can be very devastating, but it also can be very empowering.

I try not to focus on the disability, but the ability now being present.

If I can get my dad to laugh to the point where we're both having our sides hurt from laughing so much, it's a good day.

A few years ago, me and dad went out for a bike ride, and I lost him. Ended up looking for a tandem bicycle.

We would try to coordinate together on a bicycle. How to stop, how to move forward, how to balance each other on a bicycle, a tandem bicycle, and how it was invigorating for the both of us.

I get to see the benefits of riding a bicycle with my dad—together on a very complex device...but yet, simple as putting one foot in front of the other, pedaling down the road.