

How Caregiving as a Child Shaped My Life



It's May 2010. Finals are approaching, and school is about to end. Summer is imminent, promising time in the sun, camping, a vacation, and friendships.

To a teenager, having the whole summer to kick back sounds glorious. It is a time for youth to really be youth – developing abilities to manage peer-to-peer relationships and craft lifelong memories. School can provide the same, but summer also brings a sense of liberation from the educational walls.

It all sounds great. It is! However, that was not quite the childhood that I experienced – at least not as much as my friends did. Now that we've cracked the door open, let me give you a glimpse of what it is like to grow up as a child of a parent living with multiple sclerosis – a parent like my mother, Tammy.

To my knowledge, my mom's MS journey started after a blacking out while working a shift. After regaining consciousness, her vitals were checked and nothing appeared as a concern. After a handful of doctor visits, testing and hours on the road meeting top neurologists in Minnesota, she was diagnosed with MS.



Artley's family, with his mother in the center. Photo courtesy of Kameron Artley

Her outward symptoms were gradual. Her mobility transitioned from using a cane and needing a brace for her foot to using a walker, then a scooter, and eventually depending on a wheelchair and other people for mobility.

I was given a lot of responsibility. Not all at once, but more so gradually over time. Could you imagine giving an infant the responsibility of driving their mother in a van around town? Ha! Joking aside, the walker phase is when my roles began to increase, at around 8 years old. Without knowing the distress mom might have had using it, I thought her walker was the coolest thing ever. It was bright red and reminded me of a zippy sports car. Our townhome was located on top of the "hill" in our little town. Some of my earliest memories are accompanying her on walks to the grocery store and helping to carry the groceries home.

When we moved to the countryside, courtesy of Habitat for Humanity, her disease progressed. It became increasingly hard to lift herself, so our roles began transitioning to being more hands on. We assisted by guiding her into the car, parking the scooter to charge and putting the wheelchair in the trunk. Eventually, we had to get a van that we could roll her into, which eased up on the physical work and stress on her body.

While I was still able to spend time with friends, there were limitations. I often found myself canceling plans to be at home for support. She needed someone at home most of the time for her own comfort level. At some point, she was recommended to have a Personal Care Assistant (PCA). Her first PCA was her mother, Heidi, who came over in the daytime for social and physical support around the house. That is a whole different topic, the importance of community. My siblings and I would fill in when grandma's shift ended, including doing some of the more traditional chores. When mom was unable to drive, my eldest brother and I would have to drive into town to buy groceries with EBT and complete bill payments - learning how

to budget.



Artley's mother. Photo courtesy of Kameron Artley

As mom's MS developed, so did cognitive issues. She would forget about important dates, taking her medications or any of her own requests. Occasionally, she would have scares that would land her in the hospital and then in a nursing facility, requiring over a month to recover. While there was family to take care of us during that time, we would still be responsible for keeping the house running.

While I am disappointed that I happened to miss out on friendships, there were plenty of great things that I received in the time with my mother. She passed away in March of 2021 at age 49. We lost her at a young age, and, at times, it feels like 20+ years of stories and memories were stolen from me. Yet, there are many stories and memories that I cherish from the time we spent together as result of the situation.

Caregiving as a child has taught me to be empathetic in all aspects of my life. While we didn't choose for mom to have MS, it is up to us to decide how we respond. My experience inspires me to advocate and fundraise for people affected by MS on behalf of my mother. It has shaped my development and led my career path to my current role. In 2021, I joined the Upper Midwest Chapter, Walk MS Team at the National Multiple Sclerosis Society! Thanks for reading!