

The Cost of Caregiving



What can I say about my man Stan - Stan is my incredible husband, an amazing father and grandfather. He has been by my side and makes sure I have everything needed in my MS journey ever since I was diagnosed in 2007 on my 40th birthday. This includes his role as my primary carepartner.

When people think of caregiving, images of helping with daily life may come to mind. And Stan does help in these ways because fatigue is a daily struggle for me. But something people may not think about as much: his main responsibility in my MS care is to provide financial support. My personal non-profit funding source, as I like to call him.

My income comes from disability, so our main income comes from Stan. Without him, I'd have support from others like my children and mother, but income wise, it would be an exhausting journey. I'd have to work full-time, constantly fighting off being tired and risking the stress flaring up my MS. And income is important because the cost of caregiving adds up; and it adds up quickly.

Stan's job does not allow him to use sick leave to care for me, and unplanned leave is not compensated. When he has to unexpectedly take off to take me to an appointment, that is salary loss. We don't have the luxury of me waking up with a relapse and not having a backup plan. I could have a relapse tomorrow morning, and he would have to go into work. A husband should not be worried about choosing between physically being there for his wife's health or losing income that could help his wife's health.

These financial responsibilities and costs add on top of the already costly disease that is MS.

Those of you affected by MS, you know what I'm talking about – and you know that the costs of MS go beyond what insurance will approve. I would argue that MS is the most expensive disease to care for. Besides expensive medications and medical equipment that insurance may cover, there are copays and significant expenses that are not covered. Simple things like portable fans to modifications to home or vehicles can add up.

I consider physical therapy (PT) a necessary service for my symptom management. When my physical therapy's office was closed for in-person appointments during the start of the COVID-19 pandemic, giving up therapy was not an option. With the option to do telehealth, my husband and I gave no second thought to purchasing a stationary bike, elliptical, balance bars, mats and more so that the PT could do many of the same things via telehealth as we did in the office so I would not lose my gains. Was this covered by insurance? No. Did it come from our personal budget? Yes.

The cost of MS is beyond finances. The cost includes time, which inevitably makes the finances increase (cause time is money, right?). Our biggest cost is time that I cannot spend with my husband with simple things. Some evenings we want to take a walk, but I can only walk a certain distance, so I stop and wait for him to circle back, or he has to turn back with me. At the risk of losing time participating with family activities, we decided to get a scooter so I can take those longer walks with him or go to amusement parks with my granddaughter. Insurance will likely not approve a scooter because I get fatigued while walking beyond 50 feet, so that's probably a cost we will have to invest in for our time and marriage.

MS is challenging; caregiving is challenging. To pile on financial challenges and stressors on top of all this is a recipe for disaster. Caregiving allows us to tackle this disease as a unit, but its cost can sometimes ruin teams.

We need to raise awareness about the literal cost of caregiving and the undo stress it places on already stressed-out families. There are 40 million family carepartners in the U.S. providing \$470 billion per year in unpaid care, and 70% of them use their own money to cover care expenses. Policymakers, activists and our communities must push for financial relief and recognize that caregiving costs can have significant impacts for families, such as debt and forgoing savings.

Our story is not unique. Ask any carepartner, and they'll share the pressures they face financially. Let's shine a light on this issue and give caregivers the support they need.

Editor's Note: Take action in the Society's [current advocacy priorities to support caregivers.](#)