

MS: The Third Wheel in Our Marriage



As I helped my husband, Norm, out of bed, I couldn't help but think to myself: how did we get here?

It's hard to even remember the people we were when we first meet in 2006. They seem like completely different people from a completely different time. A time when motorcycles, weekends filled with friends and family and simplicity moved our world.

In December 2009, our simple lives changed when Norm was hit head on by a drunk driver. His leg was badly hurt in the accident, and he went through years of rehabilitation therapy.

But new and worsening symptoms began to appear, like spasms or extreme weakness. At first, we thought they were because of the accident. But when the spasms worsened, doctors decided to do a series of MRIs and a spinal tap.

Back and forth from the doctor we went until last spring, when Norm was diagnosed with primary progressive MS.

I was in shock. Although the tests pointed to his inevitable diagnosis, I felt I had just gotten hit by a bolt of lightning.

And we were told there's not much we can do for his type of MS.

In the months since his diagnosis, I have watched Norm quickly go downhill. Sometimes he's

incoherent when he's talking. He can stand up with help, and good days mean he can transfer from his recliner to his wheelchair.

I know he feels isolated. He can't go to our grandkids' birthday parties, sporting events or school nights. That hurts him. He misses them so much. I sometimes feel like I sit helplessly by and watch him decline.

Taking on this role as his primary carepartner has chipped away at me. How could it not?

When I am not working, I feel like I can't go out because that means he is alone more. So, I spend my free time at home. I rarely see my friends.

Our lives have changed drastically, and I am still trying to navigate this new life. I never thought I'd help my husband dress. That I would have no one to help me if I get sick.

A lot of days I feel overwhelmed, exhausted and very lost.

Our love for each other remains, make no mistake of that. But some days, this disease is a beast and gets the best of us.

There are days I snap at him and then feel horrible or days when he is so down he breaks my heart. We spend a lot of time apologizing.

I often ask myself: how did we get to this place? A place where a husband has a progressive disease. A place where his wife is trying to fight her way through this confusing, challenging uncharted territory.

But now I'm finding myself asking, where do we go from here?

MS is here. MS is in our lives. MS is in our marriage. Looking to the future, where do we go? How do we evolve our relationship and move forward?

I ask the MS community, particularly carepartners: where do we go from here, and most importantly, how?