

Life as We Know It



I recently walked our two boys to town to get pizza, and I ran into another mother from the neighborhood. She was alone and bringing pizza home for her kids because she and her husband were going out for a much-needed date night.

“It’s so important to make time to do that, you know?” she said to me, looking for relatability as I tried to wrestle a handful of napkins from my three-year-old before he tore them into confetti in the restaurant.

“Oh yeah, of course!” I said, with a nod and a smile. In my head, a few thoughts started to swirl.

Like to the last few times that my husband, who was diagnosed with MS in 2016, tried to go out for dinner or drinks. More than once, we had to change our plans because his fatigue was too great, or he had some other MS symptoms that would make the night out less desirable than just a night going to bed early.

Or that I was so jealous that she was out in town on her own without her kids when I had carted our boys in with me while my husband was home resting, battling his third case of strep this year. He had just received his infusion treatment a few days earlier, and we suspect that it weakened his immune system just enough to reignite whatever he had just recently gotten over. Our date night that night was going to be an early bedtime for the boys (and us).

Those thoughts came to me quickly, but so did this: In spite of the lack of “date nights” and

me having to do a lot of solo parenting, it is what it is, and we're doing alright. Every family has their challenge, and this is ours. And so, the best thing I can do is help our family live our lives as it is.

Our life is taking each day as it comes and not worrying too much about the future or even the past. I learned early on that just because one day is bad doesn't mean the next will be, too. Once I learned to let go of the fear that my husband's condition could turn, I felt a sense of control over a previously uncontrollable situation. This doesn't mean that we're ignorant to the reality of the disease, but we don't let it control our lives and what we do. We celebrate the good days and roll through the bad ones.

Our life is me often being the spokesperson and advocate for my husband and our family to help remind others of the challenge we face as a family impacted by MS. When people see my husband, he usually looks "normal." But they don't see his numb leg or sometimes difficulty remembering things or his usual exhaustion. They don't see how hard it is for him to be sidelined by fatigue when he most wants to have energy for me and our boys. It's my job as a support partner to help others understand what life looks like for him.

And our life is us appreciating the little things that bring joy, even if they are very little. Enjoying a nice meal cooked at home, watching our kindergartner read a full book for the first time, or playing with the dog that everyone said we were crazy for getting—all these things remind us that even in our hardest moments, we've made it through and we're okay. So we may not get out on date nights the way other couples sometimes do, but we make time to show each other that we're there for each other, even if it means we're in bed by 9 p.m. on a Friday.