

Talking to My Children about MS



Even if the sun was shining and the day was warm, I'd cringe whenever I'd drive by the park with my sons. Because I knew my 6 year old would ask to stop.

And I knew I'd have to say no.

I was newly diagnosed with multiple sclerosis, and I had trouble walking. It wasn't all the time—sometimes I got around just fine, with only low-grade vibrations going through my feet and legs. But other times, especially when walking a long distance, my leg would essentially lock up. I'd struggle to reach my destination—my office, my car.

The worst times were when this happened right before I picked up my sons after work.

It meant that I'd have to be strategic about pick-up: stop and get the 6-year-old from his after-school care program before picking up the 1-and-a-half-year-old from day care. That way, big brother could help with little brother.

It wasn't my proudest parenting moment, and it's not easy to admit it even now, more than four years later. As a parent, the last thing you want is to feel like you can't care for your own children. It's why I didn't ask for help at the time.

But if there was a silver lining to that particular struggle, it's that it opened the door to how to talk to my young kids about my illness. My stepdaughter, a teen at the time, could understand, but my sons were too little to even pronounce multiple sclerosis, let alone grasp the full implications of the disease.

So when my older son would ask to stop at the park, I'd say, "sorry, buddy, mommy's legs are tingling, and daddy's not here to chase your brother around."

For me, this was the best way to start explaining my disease to my kids. They didn't need to know the ins and outs of the illness, they just needed to understand how the symptoms were affecting me.

I'd also sometimes tell them mom couldn't walk as fast as usual because of this "leg tingling" (a pins-and-needles phenomenon common in MS, which for me sometimes led to the leg-locking-up feeling—which I later learned is muscle spasticity).

I also often had to explain to them that mommy is really tired—not just regular tired, but exhausted—and needs to rest. Or that mommy shouldn't be outside in the hot summer afternoon sun for too long.

This is still the phase I'm in with my youngest, now 5. But at 10, my older son is graduating into a different phase, a deeper understanding. It wasn't pleasant explaining to him that MS is something I will have forever—that even though I feel fine today, I might not tomorrow. But I've been proud to watch him grow into an empathetic young man who often notices when I'm not feeling quite right and is ready to help.

I'm sure that empathy is not an uncommon trait for children of parents with a chronic illness. And perhaps it's another of the few silver linings we can cling to. For all the fears I have about parenting my kids with this illness, I'm most proud of their kind, caring hearts.

Even my little guy displays this. A few months back, when I had to lie down because of fatigue, he sat next to me on the bed and said, "okay, mama. I'll sit here and get you whatever you need."

It was a heart-warming reminder that I'm not alone in this fight, and that despite everything, I already have everything I need.