

5 Things I Want You to Know if Your Parent Has MS



My mom was diagnosed with progressive MS in 1982 when I was 7 years old. By the time I was in middle school, she had to use a wheelchair full time. This was a traumatic experience for our family. We didn't know how to handle it, what MS was, if it was real, or how long this would last. Looking back, I wish I'd had someone there to tell me what my new normal was going to be like and some ways of dealing with it.

- **Talk about how you're feeling.** Nobody truly knows what you're going through, but they can get the gist of it. There's nothing wrong with talking to a therapist. But you have to be open with them or it's a waste of time. [Find a group](#) or a mentor, someone who can empathize or sympathize, or a community like [MS Adventure Camp](#).
- **Let people in.** Knowing that some of my friends understood was helpful. I wasn't very open, but I had a friend named Ryan who would spend the night sometimes and would go and talk to my mom. One time, we were out in a sailboat, and the wind was too strong for us to land on the side of the lake my car was on. So, we had to land on the other side. It was a lot of work, just landing the boat, and afterwards, Ryan said, "Gosh, I'm so tired, and we still have to walk all the way back to the car. This must be how your mom feels all the time." It made me feel like he understood some of the things I thought about. I didn't feel so alone. You can't make that kind of moment happen. But it can't happen unless you're open and let people into your life that you feel comfortable letting

in.



Me, at around 7 years old, at Easter.

- **Spend more time with the parent who's got MS.** Sometimes I didn't spend time with my mom because I was uncomfortable. I was scared. I wish I had been there more. Even if it's just sitting with them or watching a movie together one night, sit with them. Talk about them, about their childhood. Get to know them.
- **But also make time for yourself.** It's OK to get away, even just to go for a walk or sit outside. I used to hide in my closet when I was a kid just to get time by myself and try to feel safe. Maybe you need that time daily. Maybe you need it hourly. You might just need to sit and tell yourself, "It's not my fault. It's tough, but it's going to work out. It's going to be OK."
- **Sometimes things don't make sense, and that's OK.** I was angry at God for a while. I thought he could fix it, and I got really mad when he didn't. Sometimes people in your family are going to say things out of frustration. People may say hurtful things, like your parent who doesn't live with MS, but just know people have struggles and they might not know what to do. It has nothing to do with you. It doesn't have anything to do with you. Sometimes you won't fit in with people at school because of what's happening at home, and that's OK. Just be yourself. Other people can help sometimes, but they aren't always going to be there, and that's not your fault. It's not because of anything

you did. Keep reminding yourself you are in a difficult situation that is out of your and your family's control.

Everyone has their own unique journey with MS, and The National MS Society blog strives to amplify the diverse perspectives of people in the MS movement. While the content of this blog may be sensitive to some, the author is sharing his personal, authentic journey with MS.