Juggling MS and Family Life: Tips for Parenting Like a Pro With MS

by ABIGAIL BUDD

What Parenting With MS Is Like

I always thought my children were well adjusted and felt fine about having a mother with multiple sclerosis (MS). I knew they'd rather I didn't have it, but I thought they'd accepted it and had learned to live with it. I've even seen it as a positive before; they seem to be more compassionate, independent and tolerant of diversity than other kids.

Recently I've started thinking I could have taken their acceptance for granted and maybe they're not coping as well as I'd thought.

I have a 10-year-old son and a (nearly) 7-year-old daughter. My son can just about remember a time when MS didn't disable me. He was a baby when I was diagnosed so has memories of going swimming or the park with me on our own.

My mobility took a turn for the worse when my daughter was around 1-year-old. She has no memories of anything other than mommy on a scooter or needing a rest after lunch. I thought she understood it all but recently, after a long day when I was struggling to get to the bathroom, I found her sobbing.

Her little face looked stricken, and when I asked her what was wrong she said, "I'm sorry it's my fault you've got MS mommy."

I was astounded. I tried to tell her it wasn't her fault, but she must have overheard me talking about how my mobility got worse after she was born and concluded it was because of her. Then I explained that women with MS often get worse after having a baby and she seemed to accept this.

How Do You Talk About MS With Your Children?

I started investigating on trusted websites whether there were any information and support and came across a publication on the MS Trust website; Kids Guide to MS. I ordered a free copy to go through with her, but you can also download it onto your desktop.

When it arrived a few days later, we snuggled up together on the couch and read it together. It was glossy, colorful pictures and lots of information. She was thrilled with it and took it proudly to school for show-and-tell the next day. Her teacher went through it with her class, and she loved answering the questions from her friends.

This made me realize how I need to check in with her more often. I need to make sure she understands it not anyone's fault, and it's also not the end of the world.

The Importance of Checking Up On Your Children

As my son’s older he does lots to help when my husband’s at work. He can get my scooter out of the car, for example, and helps me with the dinner. I thought he was coping better, but recently I got called into his school to talk to his teacher.

She told me he’d not been himself in class and asked if everything was ok at home. I was dismayed to discover he told teachers he was worried about me when he’d been challenged about bad behavior. This seemed so unlike him as he’d always seemed fine about helping me.

A few weeks before this, he’d been upset when he was unable to help with something, and I’d considered a Young Carers group by where we live.

Find Support for Your Children

The Young Carers group is a safe place where young caregivers meet up. They can talk about how they feel about their parent’s disability, and staff takes them on fun days out.

I contacted them and was in the process of organizing an assessment when my son had a change of heart. We had a long talk, and he worries he doesn’t do enough caring to justify attending the group. He doesn’t have to wash me, for example, so would feel like a fraud. The organizer said she understood and that there’d be a place for him if he changed his mind in future.

I agreed with his teacher that we’d both keep an eye out for him and I encourage him to talk about how he feels.

It’s good to know there is help available and I would encourage you all to investigate what’s going on in your area. Keep in touch with the school as they can keep an eye on behavior they’ll be hiding from you.

I would also suggest talking things through with your children. We often underestimate how much they understand and try to protect them from inconvenient truths, but in my experience, they can cope with a lot more than we give them credit for as long as they feel loved and understood.

Next page: five tips on parenting with MS like a pro.

Being a Parent With MS

I was diagnosed with RRMS eight years ago. As my mobility has gradually declined over the years, and the “RR” has mysteriously morphed into “SP,” I've had to re-evaluate my parenting skills and take stock.

At times I've mourned in despair for the mother I wanted to be. I always imagined I'd be strong and energetic, going for long walks in the woods and coming home to bake cakes and messily decorate them with my kids. The reality is more like struggling from one task to another, praying to the 'God of MS' to be kind to me and keep fatigue at bay for a few more hours while I finish bathing the little one.

I do cope though, and some days I can hold my head up and be proud of my parenting skills. Other days, while I'm hollering at the top of my voice as its too far to hobble up the corridor, I wonder if I'm doing a good enough job.

It's the physical stuff I struggle with. My balance is bad so I use two sticks, which makes most household jobs virtually impossible. I can't carry things, so cooking and cleaning up can be a challenge.

My husband is amazing and works so hard for us all. He does the cooking, shopping, washing and most of the school runs. He has to work too, and we're lucky that he works part-time hours for a full-time salary, but this means there are times when I'm on my own with the children for whole weekends.

1. Plan Ahead

We get around this by planning our lives down to the last detail. We sit with our diaries and see when he has to work and what I'll need to do on my own as a result. I can then elicit help from other family members if necessary; my mum picks my son up from school to give me a break sometimes.

Another thing we have to plan in advance is meals. I have to cook sitting down and can't carry food to the table once it's made. My son helps a lot with this as he's seven now, and fairly sensible when he wants to be. The heat in the kitchen does bad things to my fatigue though, so we have to think about the meals I can manage.

We make huge batches of macaroni and cheese or tuna pasta bakes, which can be easily defrosted and put in the oven. I also have handy microwave bags that cook broccoli in two minutes! My husband also prepares fish with vegetables in parcels that cook in 20 minutes so its possible to cook nutritious meals as long as you plan in advance.

2. Be Creative

I also think of creative ways I can make the best out of a difficult situation. For example, I had to take my son to ninjutsu today, and it's a difficult walk near a busy road with loads of steps at the end. I had my daughter with me too, and I worry about the road when I'm struggling along at a snail's pace, concentrating on every step!

I drove instead, watched my son go in from the car, and then my daughter and I had a “car picnic” while we waited for his class to finish. She enjoyed her packed dinner and we watched the world go by, wondering where people were off to. This saved me so much energy and stress and we all got home safely an hour later.

3. Make Play Dates

Play dates are another wonderful invention. When I have the children on my own all weekend I feel like dropping to my knees in relief when someone agrees to come around with their children. I can then sit back without doing too much while they're occupied all afternoon.

4. Look After Yourself

I have to factor in rest, too. Often I bow out of going to the park or visiting relatives just so I can rest. I went on a fatigue management course recently, which emphasized the importance of cognitive rest as well as physical. This means putting my phone down and closing my eyes for an hour, and it's amazing what a restorative effect it has.

I eat really well too and have learned that MS and alcohol don't mix well, so I drink once a week these days. It sounds boring, but this lifestyle change has greatly improved my fatigue and mood, making me a better person to be around and a better parent.

5. Say Goodbye to Guilt

Perhaps the most important thing I've learned about parenting with MS is to not feel guilty. I struggled with this for years but now I realize there's so much I can do to be a good parent despite my MS, and my kids love me and need me regardless.

Sometimes I can't do everything, but as my daughter pointed out recently: “Mommy gives the best cuddles of all!” That about sums it up!