Explaining MS to Kids

by LEEANNE LAPUM

MS Through the Eyes of a Child: LeeAnne’s Story

I distinctly remember being totally exhausted after taking our five-year-old son to school, coming home and putting our 18-month-old daughter down for her nap. I’d had a busy day, or so it seemed, even though it was only 10 a.m. I laid on the couch to rest for a bit.

The next thing I knew the phone was ringing. It was my son's teacher telling me that I was late picking him up from school. I hurriedly got my daughter ready and rushed off to school. I didn't think anything of it at the time. It never happened again, because I didn't allow myself to stretch out for a rest during the morning. Everything seemed fine so life went on seemingly as normal.

When our children were in kindergarten and fourth grade, I began to experience some confusing symptoms that I couldn't ignore or explain. I made a conscious effort to keep things as normal as possible. I didn't let the kids know there was anything to be concerned about. I didn't even tell my husband at first.

I didn't have any energy at the end of the day. I finally told my husband my concerns. He wasn't surprised. He had noticed a few things but hadn't mentioned them; he didn't want me to feel like I wasn't a good wife or mother.

I began feeling pain from my upper torso down all day every day. I had experienced back problems in the past so we weren't terribly worried. There was a physical therapist that worked above my husband’s workplace. He offered to check me out.

After talking with us and working on me a bit, he asked for my physician’s phone number. I remember very clearly listening to them talk. After they got off the phone, he told me that my physician wanted to see me as soon as we could get there.

He had waited after hours to see me. There was no one else around. He asked a few questions and checked the strength and co-ordination in my hands and arms. I clearly remember him asking me to stand. He reassured me that he wouldn't let me fall. I was able to stand but not very well.

I was hospitalized overnight so some tests could be run. I was given ice to sleep on because of the pain in my back. I had done that for years at home so I didn't think much of it.

Next page: more tests, diagnosis, and telling the children.

More Tests

The next day I was taken to have an MRI taken of my spine. That in itself was a strange experience. They had me take valium in preparation for the test. Looking back on it I can see why. I was asked to lie down on a slab that

stuck out of a large mechanical tube. I was eventually backed into the tube. There was a lot of noise as pictures were taken of my spine.

A few days later the neurologist that had ordered the test called. Because nothing had shown on the test he wanted me to come in for an MRI of my head. That time I was prepared. The dark tube with its strange noises wasn't nearly as alarming as it had been the first time.

After, we went home to our young children. They, of course, asked a lot of questions. We had decided ahead of time to make it exciting for them. We made it sound more like a carnival ride. We wanted them to think that all of this was a big adventure. We were successful. They went out to play.

The rest of the week was uneventful other than occasionally stumbling which I managed to brush off. I received a call from my neurologist the next week to discuss the MRI results. By that time our children thought nothing of my visits to the doctor. It was just another opportunity to play with their grandparents.

Diagnosis

We were seated in an examination room. The neurologist that had been assigned to my case entered the room. He casually hopped up on the examination table as if to have a ‘chat’. He explained that my problems weren’t related to my back. He went on to tell us about the different types of MS, including the untreatable chronic/progressive, which is the kind I have.

He was able to prescribe something to ease my daily pain so that I could function, but there was nothing more that he could do. We were determined to make our lives as normal as possible. We told our children that mommy was “sick”, but didn't go into a lot of details. There was so much we didn't know ourselves.

Over the years we have learned to function on a somewhat normal basis. Our once young children are responsible adults. They have actually assured me that because of my illness they are more sensitive to others. They have thanked us for helping them learn to deal with difficulties that most kids never have to experience. They have told us how much they admire us for sticking together under circumstances that many would have let tear their families apart.

They are stronger because of my illness and the way we handled it over the years. They are more prepared to rise above challenges and conquer them. They are responsible, confident adults, and that warms my heart and strengthens my spirit.