

How Does My MS Impact My Kids?



Although I do my best to function like a “normal person,” I know that my MS has an impact on the rest of my family. My husband often has to take on some of the household duties when I become fatigued or overwhelmed, and it can be very difficult for me to hold my own in a conversation after 8:00 pm.

What I worry about the most, though, is the effect that my MS has on my twins. I once heard a saying, “Parenting is the hardest job in the world if you are doing it right.” Sometimes it feels like “doing it right” is almost out of reach when one of the parents has MS. With an estimated 2.3 million people in the world living with MS, a disease typically diagnosed between the ages of 20 and 50, there are clearly millions of children who are in an MS-affected family.

I was excited (and a little nervous) to hear a lecture at [ECTRIMS 2013](#) on this topic by Julie Yoon Skodshoej Moberg, a nurse at the Danish MS Center, entitled, “The implications on children who have parent(s) with multiple sclerosis.” Ms. Moberg presented the results of her extensive literature review, summing up 25 articles about children in families where one parent has a chronic illness. I was anxious to see what researchers had discovered about this topic, but of course, I also wanted to see if I was doing okay and if there were major pitfalls that I could avoid as a parent with MS.

Not surprisingly, the research that Ms. Moberg presented demonstrates that physical disabilities and cognitive dysfunction related to MS (and other chronic diseases) certainly complicate parenting. As a result, some “side effects” of these problems that can cause difficulty in a family include:

- Lower income or complete loss of employment, due to inability to maintain a certain profession.
- Less spontaneity and participation in family activities because of fatigue.
- Chores and household tasks take longer to do or cannot be done.
- Separation from spouse, attributed to MS, can occur.

In addition to these tangible results of MS, the research shows that there are also psychological effects of living with a chronic disease. Life stressors seem to have a much greater negative impact on the whole family, perhaps magnified by persistent thoughts by parents that they are not living the lives that they imagined for themselves or that their parenting is not the parenting that they wanted.

What does this mean for the children of parents with MS?

- Children can experience stress caused by worrying about the health of the parent with MS and what disease progression may mean for the family.
- It can be time-consuming to help parents with household chores, as well as the parent's own daily activities in some circumstances. One 12-year-old girl who was surveyed said that she felt chronically exhausted, since she did the majority of the cleaning, shopping, cooking, babysitting and helping siblings with homework.
- If parents need help with their own personal hygiene, it can be an additional physical and psychological burden on children. In one extreme example, a 14-year-old boy reported that he was extremely uncomfortable having to help his mother in the shower.
- The child's social life may be impacted negatively if they are apprehensive about bringing friends home, due to his or her parent's disability.

Lest we fear that we have irrevocably damaged our children, I am happy to report that there are likely some positive aspects of having a parent with MS. Some of these kids reported that they were:

- More self-reliant
- More independent
- More responsible
- More helpful
- More sensitive to the needs of others

In short, it seems like in some cases, having a parent with MS helped children mature more gracefully into a better citizen of the world.

What is recommended to parents with MS taking care of kids and themselves?

- Be honest with them about the MS, as soon after diagnosis as possible. This allows the whole family to cope with the MS as a team, and avoids the situation where the child feels isolated when they find out later.

- Get social support for the parent with MS, healthy spouse and kids – either formal or friend network. Reduces stress.
- It is a big challenge when kids have to take care of intimate hygiene. It's better if they don't – children have right to be children.

One participant made the very astute observation that, until recently, most studies of MS in families focused on psychopathology occurring in children of parents with MS. Now it seems that attention is turning more towards investigating coping strategies to identify tools to help families.

While this presentation reinforced many of the things I had already figured out through personal experience, it reminded me that children, especially young ones, live in a very small world, of which the parents are a very large part. Anything that makes a child feel different can lead to feelings of isolation. Do your best to make your child feel like MS is just one factor in the family and remind him or her that every family is different and everyone has their challenges. While the words may ring empty at times to your ears, acknowledging the MS, but not focusing on it, allows children to cope with it in their own way.

Editor's Note: Below are additional resources:

- [Parenting with MS](#)
- [Keep S'myelin: A Fun Resource for Kids about MS](#)
- [Someone You Know Has MS: A Book for Families](#)