

Life When Your Teenager Has MS



About 5% of people diagnosed with multiple sclerosis are under the age of 18, usually as teenagers (for clarification, MS is classified as “[pediatric](#)” if it occurs in a person younger than 18). As remembered by pretty much every adult, this is a challenging time for virtually everyone, emotionally, socially, mentally and physically. Throwing in a diagnosis of MS can only further complicate matters as a young person is trying to figure out who they are and who they are becoming.

This is a difficult time for parents, as well. For parents of healthy teens, this is a period of learning when to let go, when to be firm and when to compromise. Many teens question their every move, just as their parents question many of the parenting decisions that they make throughout each day. In a study done on parents’ experiences of pediatric MS presented in a session entitled “Parent experience of pediatric multiple sclerosis” at the 2014 Joint ACTRIMS-ECTRIMS Meeting, all of these same dynamics and feelings seem to play out, but in a much more intense way.

Parents are much more cautious: Understandably, parents become extremely protective of a child with a chronic illness. They focus on what the child is doing that may cause them to feel worse, and worry when any symptom worsens. Kids, on the other hand, tend to focus on what they can still do and how to work around limitations. Like virtually every teenager, they want to feel “normal” and have others perceive them as such. This divide between what kids think they can handle and what parents think they can understandably leads to tension between adolescents with MS and their parents.

Parents are more forward-looking than kids: From the moment a person becomes a parent, he or she starts worrying about their child’s future. You look at the tiny infant or the

tireless toddler and wonder about what his or her life will be like decades from now. Meanwhile, children are only focused on how they feel at this exact moment.

The study showed that when the child is a teenager with MS, these emotions get amplified in both parties. The parents have a whole new set of worries to contend with, including thoughts of increasing disability and hardship for their children. One woman talked about the sadness and stress that she felt when she saw someone in a wheelchair going into the same clinic as her daughter, wondering if that was her future. The teenagers with MS in the study took a different approach, tending to “not think about MS” on days that they were feeling good.

Parents deal with their own emotions in various ways: Just as we all find our way in dealing with different situations, parents react in very different ways to their child’s MS diagnosis. Some report feeling emotions along the lines of “Why me? Why my child?” Others turn into activists, becoming involved in their local MS Society chapters and working to raise awareness. Interestingly, many parents reported relief that the final diagnosis was MS, as they had spent the months leading up to diagnosis worrying about potentially fatal diagnoses, such as brain cancer.

Bottom line: Nothing here is too surprising. It just sounds like a very extreme case of teenagers being teenagers, and parents being concerned about their children. Two pieces of advice were offered, however:

1. Let your teenager do the activities they want. Let them determine what they physically can and cannot do; they will learn to adjust their activities to their abilities and energy levels.
2. [Find support groups](#) for yourselves, as parents, and (separate) groups for your children. It is very important for young people to find others like themselves, and often, nothing helps parents like another parent saying, “I know exactly what you are going through.”