



**MS Learn Online
Feature Presentation
Parenting with MS
Debbie Miller**

Tom>> Hello, I'm Tom Kimball

Tracey>> And I'm Tracey Kimball. Welcome to MS Learn Online. We all know that MS has an impact on the entire family. Children who have parents with MS naturally have concerns about the disease and often take on extra responsibilities.

Tom>> How parents communicate with their children and help them with the adjustment of living with a chronic illness in the family is very important.

Tracey>> Dr. Deborah Miller from the Cleveland Clinic explores this topic with medical correspondent Rick Somers and gives good tips on helping with the transitions that many families living with MS need to make.

>>Rick Somers: Do you work with families from parents through diagnosis to their kids coming in as a group, as a family unit?

>>Deborah Miller: Yes. We have education programs for children by themselves, because sometimes there are questions that they're uncomfortable asking in front of their parents. We've done group

programs with both grade school age and teenagers, to help them learn more about MS and express their feelings. And we certainly do couples counseling and family counseling as well.

>>**Rick Somers:** So, I'm a newly diagnosed parent, and I want to come in and talk to you and talk about how I'm going to broach this with my kid or kids. What are some tips, what is the best way to handle it as far as letting the little ones know what's wrong with Mom or Dad?

>>**Deborah Miller:** That's a really common question and it's a very important one. The first thing to understand is that children are very intuitive people. And in my career I've come to understand that they really appreciate the nuances that their parents exhibit either in terms of their physical wellbeing, their emotional functioning. They notice if their parents are spending more time at the doctor, or if they suddenly started taking an injection.

Children have very active imaginations, and they tend to make up explanations if they don't have them given to them. So, oftentimes what children are imagining when their parents are newly diagnosed is actually often worse than going through the diagnosis about MS and starting --

>>**Rick Somers:** Not much different for the actual patient.

>>**Deborah Miller:** Exactly. So, I encourage parents to always be factual and very much in the present about what's going on. That they're seeing the doctor because they have a diagnosis, and that it's something that they're going to be dealing with for a long time, but that the child is not responsible for. I think that that's key. Because a lot of times children internalize and take on responsibility for what's happening in their family, and parents need to send the message that they haven't done anything to cause this.

>>**Rick Somers:** Right.

>>**Deborah Miller:** And to answer the questions that children have at the educational level of the children. Don't go into *War and Peace* when they want to know why you're having problems walking.

>>**Rick Somers:** Of the kids that you see of the parents who are diagnosed with MS, if there was one question that was most prevalent, what would it be?

>>**Deborah Miller:** There are actually two. One is if their parent is going to die, and the second is if they're likely to contract MS themselves. And we're fortunately able to tell them that their parent is not going to die, and that MS is not a disease that a person catches from their parent.

>>**Rick Somers:** Do you notice an age where some kids -- and, of course, this depends on the family system and dynamics of the family -- but a certain age where kids either choose to deal with it, deal with it better, or don't deal with it at all, or is it really on a case-by-case?

>>**Deborah Miller:** It's very much on a case-by-case basis, and I think that to the extent that the parents are able to normalize MS as part of their life, their children follow that example. It's also important to appreciate that kids growing up and turning teenagers have their own set of life experiences that are completely independent of their parent having MS. Sometimes people attribute their children progressing toward adulthood as because of the MS, when in fact it's just normal maturation. So, not all roads lead to MS.

>>**Rick Somers:** It's interesting, when I was diagnosed many years ago, my mom asked the question, "Did I do something wrong?" And I'm sure you probably see a lot of that.

>>**Deborah Miller:** Yes.

>>**Rick Somers:** I wanted to ask you, when MS does come into the household, roles are redefined, and the kids in some cases will pick up some of the slack. Tell us what you see and how you might help facilitate a smooth transition in redefining roles.

>>**Deborah Miller:** Okay. First, I think it's important to say that we have good data that demonstrates that children whose parents have MS grow up to have normal, healthy lives, normal relationships, normal careers.

As with most of my approaches to dealing with MS, I think it's very important for family members to sit down and to talk about the changes, how the parent is affected, in a playful way, in a way that all of the family members participate in. Decide how jobs are going to be reallocated so that it's not just the child is told, that, "Now you're going to be cooking every third night of the week," but that people are able to identify what chores they want to take on and they do so more willingly.

I think it's important to build in rewards. When a family is working well together, so that they don't have huge rewards, like trips to Disney Land or something, but small, daily celebrations within the family.

I also think it's really important to be flexible. There can't be one set of expectations that are carved in stone. It can't always be that way; there has to be room for modification either because of the parent's MS or because of the child's school or sport activities.

I don't think that there are many activities that are inappropriate for children to participate in within the household. Where we really strongly draw a line about what a child does is regards helping a parent with personal care. We think that that's inappropriate and should be avoided at all cost.

>>**Rick Somers:** You've alluded to before and used the word flexibility, and that really is paramount. Because being able to revise your roadmap as a parent and as a child of a parent who has MS, obviously it's a little tough for a young one to intellectualize. But as a parent, is that what you would think as probably the biggest challenge that you face in your practice in dealing with families that are dealing with MS diagnosis?

>>**Deborah Miller:** Yes. It really is learning to have the consistency that is so important to families, but also the flexibility to recognize that we're doing something different this time, but we'll be back to normal as soon as we can.

>>**Rick Somers:** Do you have some tips? You had mentioned talking, communication, as far as everybody being on the same page. Strategies, I mean, is it a monthly meeting? Is it a weekly meeting? Is it as simple as everybody sitting down and having dinner together and talking about their lives?

>>**Deborah Miller:** I think the more you're able to normalize multiple sclerosis and dealing with it the better. So, I don't think that it should be one meeting that is a special meeting, but it should be more in the normal daily course of life within the family.

>>**Rick Somers:** Are people reticent to come in under the auspices of talking with a therapist, especially if they weren't open to that themselves, now they're bringing the whole family in, and this is the 800-pound gorilla sitting in the middle of the room. Are people resistant?

>>**Deborah Miller:** In our practice, what we tend to do is introduce individuals and families to the idea of the benefit of therapy from very early on in the disease. We explain that this is a condition that's full of bumps and unexpected events, and the sooner you have an established relationship with a therapist that you feel comfortable with, you're much more likely to go back to that person

when you do hit a bumpy spot. So, we try to make the idea of working with a therapist just as reasonable and just as appropriate as going to a physical therapist or an occupational therapist.

>>**Rick Somers:** Give me something positive that I can take with me right now.

>>**Deborah Miller:** I think that children whose parents have MS and approach it in a very forthright way grow up to be really mature and contributing adults.

>>**Rick Somers:** Interesting. And they grow up quickly when they're dealing with something like this in their house.

>>**Deborah Miller:** They do. The other thing that I would just like to mention is that the MS Society has incredible materials for children whose parents have MS. They have online activities, they've got great books, educational materials, and also a workbook that's full of fun things for kids at different ages. So, the Society is really focused on the importance of children and how they manage when their parent has MS.

Tom>> Good to know. Taking advantage of those resources can really help your kids with making all those adjustments that come with living with MS.

Tracey>> As Dr. Miller pointed out, simply taking the time to talk about the disease and providing honest information are critical in living well with MS, for yourself *and* your family.

Tom>> Thanks to Dr. Deborah Miller for her passion and wisdom, and thank you for joining MS Learn Online.