



**MS Learn Online
Feature Presentation
MS and Your Emotions, part one
Deborah Miller, PhD**

Tom>> Welcome to MS Learn Online I'm Tom Kimball.

Tracey >> and I'm Tracey Kimball. Receiving a diagnosis of MS can be overwhelming as you try to learn about the disease and try to work through the many emotions you are likely to feel.

Tom>> In a two-part series on MS and Your Emotions, Dr. Deborah Miller from the Cleveland Clinic's Mellen Center talks with correspondent Rick Sommers about some common emotional reactions that people experience.

Tracey>> In our first installment, Dr. Miller begins with how people react when they first hear the words, "you have MS."

>> Rick Sommers: So, somebody is newly diagnosed and there is just a wide swath of emotions and reactions, and what are some of the things that you as a mental health professional may see?

>>Dr. Miller: Surprising to some, relief is a fairly common reaction. They probably have seen many doctors, had a wide range of diagnoses, some of them possibly terminal. And to hear that it's MS and it's a lifelong chronic condition is a far better deal than a brain tumor that's going to take your life in a couple of years.

Some people are very angry, and I think that the anger comes from them feeling completely out of control and having no responsibility for having this condition come on them. And often the anger also relates to not knowing about the disease. And that anger can be really a roadblock to moving forward. And I think that we as healthcare professionals need to pay attention to those people who are angry, because it can spill over to lots of other aspects of their lives.

Both anger and denial can delay people initiating treatments that can be very important early in the disease, so that more attention, more follow-up, more concern expressed I think is important when we see that anger and denial early in the diagnosis.

>> **Rick Sommers:** What do you say to a patient who says, "But why me?"

>>**Dr. Miller:** I say, "There is no reason why you." And a lot of times people have very magical thinking about where their diagnosis came from, and it's usually as some form of punishment. And it's important to listen to what they're being punished for and help them respond to that, but to disconnect it from the diagnosis of MS.

>> **Rick Sommers:** And the other thing is that you're diagnosed with MS, I'm married to you, I also now have MS, because it's part of my life. So, it doesn't just affect the one person; it affects the whole family system.

>>**Dr. Miller:** Absolutely. And we try to instill that in people as much as we can early on as well. At least at our center we encourage people to bring partners, those who are important in their lives, to appointments, so that they -- two ears are better than -- two sets of ears are better than one. And sometimes there are questions that may not be important to the person with MS but are really essential and screaming for the spouse or the partner.

>> **Rick Sommers:** It's a very private issue when you're diagnosed with MS or any chronic illness, and then comes the element of disclosure and the elements of who your care team is, who your caregivers may be. And these are some of the anxieties that people go through when they're diagnosed.

>>**Dr. Miller:** Yes. That's certainly true. It's somewhat easier if you're going to an MS specialty center, where you've got an entire team around you, such as we

have at the Mellen Center. But if you're not in that position of having an immediately available coordinated team, it's important to identify what your priorities and what your current needs are, and to seek out those healthcare professionals -- and I'd like to say that oftentimes that should include a mental health professional from the beginning -- to become familiar with your symptoms, your approach to your treatment, and to figure out how the coordination of care among these outside professionals is going to occur.

But also to just set the stage for, "We're here to help you; you don't need to see me right away, but as you have questions, as your family has questions about what this means in your life, we're available to talk to you," and just to have that first contact and to make it easier to schedule a follow-up.

>> **Rick Sommers:** It reminds me of when I was diagnosed. One of the things I loved was knowing that the MS Society was there if I wanted them. In other words, I could pick up the phone and say, "What programs, what's available, what can I pick and choose from?" I didn't have to sign up for anything and all of a sudden start attending meetings, but to know that they were there after I was diagnosed. Because that in itself is such an isolating process.

>>**Dr. Miller:** Absolutely. And I think the way that Society approaches individuals with newly diagnosed MS is really useful, because they really do put you in the driver's seat and let you determine what it is you want to learn and for you to set the pace for that learning. And any good mental health professional that you're working with should do that. There is so much to learn about MS and there is so much to deal with about MS, that it's very important for the person with MS to sort of set the direction for what issues are being addressed.

>> **Rick Sommers:** One of those issues is the uncertainty that this disease seems to wash over everybody, the question marks. When is the next flare-up going to be? What is the next flare-up going to be? And how do I anticipate and deal with that? How do you deal with your population that may have those questions?

>>**Dr. Miller:** First of all by acknowledging that uncertainty. By saying, "Yes, you're absolutely right," and that anything could happen at any time. But the likelihood that every day is going to be totally different is very unlikely. It's very important for people to set their priorities both on the short-term and the long-term,

so that they know that if they can't do something today that they'll be able to do it tomorrow, that there's a backup plan.

It's also really important for people to build on the successes that they've had. One of the typical questions that I ask when someone is really suffering through an exacerbation was how did you handle your diagnosis? What was effective about how you handled it and what wasn't? Let's focus on not doing those things that were roadblocks for you and really build on your successes.

>> **Rick Sommers:** And that plays right back to self-esteem, and what chronic diagnosis does to you is it knocks you down a couple of pegs on the ladder. And then when you go through having to ask for help, needing help, and the fear and the anxiety and all these things that get thrown into the pot, your self-esteem really can take a beating.

>> **Dr. Miller:** Yes, it can. And there are several things about that that it's important to keep in mind. One is that they're not alone in dealing with this diagnosis, and that I think either in-person support groups or online support groups, professionally led or peer support led, can be really helpful for making this an isolating experience. Most people don't know another person with MS, and they don't have a chance to compare notes and to get a sense of what's a normal reaction.

In terms of self-esteem, I think part of the job of living with MS and part of being a health professional dealing with people living with MS is to help them keep a fluid sense of what defines them. It's not that you're an athlete, it's not that you're a person who used to be able to go two jobs and then come home and do all of the housework. What you do is not necessarily who you are, and that can be a very difficult transition, especially for very type A people to make.

And sometimes it's really useful to put away some of the things that you can't do. An example that I can think of is that when a fellow who was a really avid softball player recognized that he wasn't going to be playing anymore, he took up coaching and he donated his equipment to a charity so that the equipment went on and he found a different way of participating in a sport.

Tracey>> I couldn't agree more with Dr. Miller's comments on the grieving process one goes through when living with MS. Fortunately part of that process is acceptance.

Tom>> Yes and if acceptance doesn't come for some, they may deal with depression. That's where we pick up our conversation with Dr. Miller during our next program on MS and Your Emotions.

Tracey>> We'll see you then.