

MS Learn Online Feature Presentation MS in a Personal Relationship Deborah Miller, PhD

Tom>>Hello, I'm Tom Kimball

Tracey>> And I'm Tracey Kimball. Welcome to MS Learn Online. I'm very pleased to introduce this program with my husband and care partner, Tom.

Tom>> As a husband of someone living with MS, I think it's important to learn as much as I can about the disease and what we can do to manage it together. Although I don't endure the physical symptoms, I too, am living with MS.

Tracey>> Dr. Deborah Miller is a social worker at the Cleveland Clinic. One of her specialties is caregiving. She sat down with medical correspondent Rick Somers to talk about how MS can affect a couple's relationship.

>>Rick Somers: When we get married, set up norms and a design and roles for what the marriage will be, and then we get thrown this curveball. Talk to me about, through your practice and your experience, what you've seen as far as marriage and MS, and how the two play.

>>Deborah Miller: Sure. What strikes me very clearly is that MS in marriage is a very unexpected event for most people. When you talk about norms, you're talking not only about how a couple comes together, but how they compare themselves to other people of their own age and own socioeconomic status. And they sort of gauge themselves based on that.

When a couple is dealing with multiple sclerosis, they really don't have any examples to follow, so that they're really struggling and making up their story as they go. And it's very important for people to have good, solid communication and to be able to discuss both their feelings and the concerns that they have. Because there are concerns, and if they go unspoken, they start as little sores but become open wounds.

>>Rick Somers: Right.

>>Deborah Miller: So, we really encourage people to be open and honest about what their concerns are, and to begin to make a plan. It's never too early to plan for how you're going to manage what may not be the trajectory that you expected, either financially or in terms of career.

>>Rick Somers: Segueing, because I want to use one of those great psychological terms and to kind of test your water on this and see, and that is denial, and how that impacts either me as a diagnosed patient or you as my diagnosed spouse. You talk about coming to terms with the diagnosis, and then the acceptance and the importance of that acceptance in being able to admit we have a problem before we can actually move on and deal with it.

>>Deborah Miller: First, I would actually suggest that nobody ever comes to accept MS. They become more effective in dealing with it and managing it, but there are so many changes that people face that it's more of an ongoing accommodation. And, again, communication is a key part of that. Denial can be very healthy, so that people don't

catastrophize and become concerned that their life is over. So, we find that there is such a thing as healthy denial.

What becomes a problem is when one person wants to say, "Okay, I've had an exacerbation, I've had my second one, we've confirmed the diagnosis. I really want to go forward and prepare for this." And the other person is not quite at that same point; they're more interested in holding back.

We work a lot with couples to learn to appreciate and accommodate their different coping styles, because not everyone copes the same way. And just as you may have differences of opinion about politics, we try to help people accommodate differences in how they approach MS, but to be able to come together for important planning issues.

>>Rick Somers: Yes. Well, what you're saying is applicable across-the-board, whether MS is in a marriage or not.

>>Deborah Miller: Exactly.

>>Rick Somers: I mean, in dealing with today's stressors as a family, where both people are probably working, then you start to bring in kids and in-laws, and job loss, and everything else. What are some of the strategies you try to educate couples that you work with? What are some good ways to get them over the hump?

>>Deborah Miller: I think it's really important for them to not automatically give up everything that has made them a couple. Sometimes people will say the core of our relationship was that we liked to do sports together, or that we were opera fans together, and one person can't stay up late anymore at night. There is usually, in addition to the love and the emotion, there is some sort of activity that keeps a couple together as well. And I think that people really need to carefully consider what that is and how they can manage to keep it going in a different way than they have in the past, and to

learn new ways to be together. That can be in terms of how they play, how they have sex, how they interact with their children. People need to be flexible, and it's a constant thing.

One of the things that I find is beneficial about having a therapeutic relationship established with people is that the therapist has a really good idea of what the strengths of the couple are, and what they've been through, and how they've overcome obstacles, and how they've come out on the other side. And when they face a difficulty again, when they come back, you're really in a position to help them recall their struggles and their victories, and help them to move forward from that point.

>>Rick Somers: In talking about progressive MS, what are some of the issues that care partners are commonly facing that you see?

>>Deborah Miller: The thing that I am warning care partners about and are most concerned about is that they don't lose themselves in the process of caring for their loved one who has MS.

>>Rick Somers: You have success stories, or one that maybe you would share? And you don't need to be specific.

>>Deborah Miller: A very young couple both with very active careers who were on a trajectory, that they were living parallel lives and were sort of passing, cross in the hallway. And the MS was really a wakeup call. It made them both rethink their priorities. Neither of them gave up their career, but they certainly reallocated their time and their commitments.

>>Rick Somers: That's one of those feel goods that keeps us as mental health professionals moving forward, hopefully.

>>Deborah Miller: It really is. Absolutely.

>>Rick Somers: Closing thoughts that you might have?

>>Deborah Miller: I would say that I've talked to many people who say that MS is the best thing that's happened in their lives.

>>Rick Somers: Really?

>>Deborah Miller: Yes. It's really caused them to reevaluate, recommit, and that we as mental health professionals can help people do that who are struggling to do so. And I think that's a very important part of our job.

Tom>> Once again communication and education play a big role when two people are working together and living with MS.

Tracey>> The other point that stood out to me is accommodations. We often hear that term when speaking about employment issues, but it has a place in relationships as well.

Tom>> The National MS Society has a great program for couples called *Relationship Matters* that helps them work through some of the big issues that make living with MS difficult.

Tracey>> From financial planning to issues with intimacy, from planning career choices to simply having fun together. *Relationship Matters* will give you some great insight and skills that will help minimize the impact that MS has on your lives. Just click on the "resources" button on the screen to learn more.

Tom>> We'd like to thank Dr. Deborah Miller for being with us. And thanks to you for joining us on MS Learn Online.