



MS Learn Online Feature Presentation

Mood Changes and MS: Emotional Impact on Family Featuring: Sarah Minden, MD; David Rintell, PhD; Rosalind Kalb, PhD

Cary: I try to acknowledge the effect that the disease has on her, but oftentimes I'm so wound up with how it's impacting me, I lose sight of how the disease is affecting her, how my behavior is affecting her, so I tend to be less sympathetic to her complaining.

William Sr.: Because I'm trying to be understanding and I'm trying to control my mood at the same time, because I don't want to initiate anything that would make it escalate.

Chris: You get at a level and you think, okay, if it's going to stay this way, maybe I can deal with it and we can still have a life. And then he has an exacerbation, blows up and now your normal is down here, worse. And then after a year, okay, maybe if it stays like this I can deal with it. And then another one. When is it going to stop?

Jay: I tried to do my best, as much as I could, to be strong. But over time it really kind of gets to you.

Tracey: I realized a long time ago that the impact of MS extends far beyond my own body. Our entire family is affected by this disease, much like the people you just heard.

Tom: As a care-partner, I try to do my best to help Tracey as much as I can. But I have to admit, there are times when it's overwhelming. That's when we both need to turn to the professionals to help us work through these difficult times.

Tracey: We continue our conversation about mood changes and MS with Dr. Sarah Minden, Dr. David Rintell and Dr. Rosalind Kalb.

Dr. David Rintell: Yes. If you live with someone who has MS, you live with the impact of MS, and the way MS affects your life can be as significant and as powerful as it is for the person who has MS as the patient. For example, it has been shown that caregiving spouses -- actually, this is across chronic illnesses -- are six times more likely to experience depression than other spouses. That the impact of living with a chronic illness, helping to care for someone, dealing not only with what may be their physical demands or problems, but also their emotional demands, can be very, very wearing on family members. And family members, like all of us, are subject to all kinds of emotional reactions to that.

There's also -- most people, although when we get married we say the vows in sickness and in health, but we don't really -- it is not our expectation about what life will bring. And there can be a sense of disappointment that, gee, I was really thinking about traveling around the world or climbing Mount Kilimanjaro, and here I am at home and I'm caring for someone and that's not really what I bargained for.

So, there can be frustration and a sense of loss and grieving for the ideas about life have changed, if not have been lost. Sometimes that frustration can reach levels in which case people start acting towards their family member or partner who has MS in ways that they wouldn't like other people to see. And if you're experiencing that, that may be an indicator that that is time for you to seek some help from a mental health professional or from a clergy person, because your level of frustration has exceeded your ability to handle it in the way that you would prefer to handle it. And that would be natural. Often, frankly, it can be frustrating being married or living with any family member, but somebody who is living with an illness can often have periods of time that either they are depressed and irritable or just very frustrated and angry and not fun to live with.

So, those are instances where family members really would be wise to seek help from the mental health professional. Often with a person that they are caring for, because we don't live in a vacuum and we're not isolated individuals, we live in families, and the family really should be seen as the unit of treatment when there are interpersonal difficulties that arise out of the difficulties and struggles of doing well and living with a chronic illness.

Dr. Sarah Minden: I really want to emphasize that, because family, care partners, family members get filled up with emotion of all kinds -- grief, sadness, anger, frustration. And I've had people come to me who say that they feel too ashamed to say that they're not loving and helpful all the time; that they feel too guilty to take time for themselves, whether it be to do something that is fun or even to come and talk to a mental health professional, that they are not the one who has this illness. And to be able to say that that's okay, this happens and I need as much help right now so that I can help my loved one.

Dr. Rosalind Kalb: You know, I think it's commonly said by people who are impacted by MS and by MS health professionals, that when one person in the family gets MS, the whole family is living with that impact.

Dr. Sarah Minden: That's right. It's a family illness.

Dr. Rosalind Kalb: And so everybody will have their own emotional reactions to it, and nobody's emotions are more important than anybody else's emotions. And so the way to meet the challenges of MS is to make sure that each person in the family is able to function and feel his or her best. And that means paying attention to these emotional challenges.

Dr. David Rintell: Now, we are here to talk about the problems that people with MS and their families experience, but it really needs to be said that most families do really well addressing the challenges of living with MS. And most partners are able to support their partner with MS very, very effectively. Now, that doesn't mean that they don't need support, and I would really encourage any partner or family member to call the MS Society or the other organizations and look for occasions to get together with other family members to exchange ideas and experience. But, again, to emphasize that most families do very well living with the challenges of MS.

Dr. Sarah Minden: Just like most people with MS do very well living with those challenges.

Dr. Rosalind Kalb: That doesn't mean that even as they're doing well they won't be experiencing some of the painful emotions that we have been talking about.

Dr. Sarah Minden: Life has rough patches, and rather than push them under the carpet, better to bring them out, talk about them and get some help with them.

Dr. Rosalind Kalb: So, I guess another way of saying this is that nobody needs to do this alone.

Dr. David Rintell: Right.

Dr. Rosalind Kalb: And particularly at times when you're feeling overwhelmed by challenges, to keep that in mind, that there is a lot of help out there. You just need to reach out.

Dr. David Rintell: Right. We are a community, and just like the joke, "I wouldn't join any club who would accept me as a member," people sometimes are reluctant to join the community of people living with MS. But once you get over that hump, most people find it to be tremendously useful to engage with the other families and individuals living with MS.

Cary: I participate in two support groups, two different support groups on a monthly basis. So between the two we talk about a myriad of issues, and the one issue that is recurring almost on a monthly basis is the fact that spouses in MS relationships don't receive enough acknowledgement regarding what they provide in terms of support and what they go through in terms of stress and the impact of the MS on their own lives.

Jay: Being a caregiver, obviously, is tough work. I find that I have to have some kind of a release of some sort. She allows me to do that. She reminds me all the time how much I mean to her, and it makes me feel good. So, the words that she says is very critical and very important to me.

Chris: I saw a therapist for, I don't know, six months maybe. I kept saying, "I feel like I'm just complaining and not getting anywhere." She said, "I think you're very brave."

Jay: I can pick up the phone and call my sisters at any time and they always ask me how I'm doing.

Cathy: And that's important.

Jay: Exactly! One word - together. You're in it together, end of story.

Tracey: Remember, if you have MS, it doesn't mean that you have to live with these painful mood changes. These problems deserve to be diagnosed and treated so that you can get on with life.

Tom: Thank you for joining us for this special edition of MS Learn Online. Be sure to check out the other programs in this series on Mood Changes in MS.

Tracey: If you would like more information on mood changes, or other issues relating to MS, go to NationalMSSociety.org. I'm Tracey Kimball.

Tom: And I'm Tom Kimball. Thank you for joining us!