



MS Learn Online Feature Presentation

Mood Changes and MS: The Role of Healthy Grieving
Featuring: Sarah Minden, MD; David Rintell, PhD; Rosalind Kalb, PhD

Cathy: I hate the phrase of, "Well, you look so good," It's not the outside, it's the inside, and all the damage that's going on in there.

Cary: I haven't worked in 11 years, thanks to the MS. And that impacts my mood on a regular basis.

William: You're going to have good days and bad days but you can do it.

Tracey: If you're living with MS, whether you have the disease yourself, or are living with someone who does, you know that the impact of the disease can go far beyond physical symptoms. For those of us with MS, we know that the disease can often come with mood changes that can dramatically affect our well-being as well those with whom we live. Hello, I'm Tracey Kimball.

Tom: And I'm Tom Kimball. In this seven-part video series, we'll explore the many ways that mood changes can affect the lives of those of us living with MS. We'll hear from people who have MS and their care-partners as they candidly tell us about their own personal experiences.

Tracey: We'll also hear from some leading experts who help people recognize, understand and treat the many ways that MS can affect our emotional well-being. We'll hear from Dr. Sarah Minden, who is a psychiatrist at the Brigham and Women's Hospital in Boston, and a professor at Harvard Medical School. Dr. David Rintell is a psychologist who is also with the Brigham and Women's

Hospital in Boston. Finally, Dr. Rosalind Kalb is a clinical psychologist and is the Vice President of the National MS Society's Professional Resource Center.

Tom In this series, we'll look at some of the most common types of mood changes including grief and loss, depression, anxiety and mood swings. These conditions often are under-diagnosed and under-treated because they can be easily confused and misunderstood. We'll also look at how these mood changes affect care-partners and family members. And finally, we'll look at what professional support is available to help you work through these difficult issues.

Tracey: Like many people who are diagnosed with MS, at times I feel a deep sense of grief and loss even right now as I'm experiencing a relapse. Grief and loss are common reactions for many of us living with MS.

Dr. David Rintell: Some of the losses that people experience in MS are surprising to them and hard to get a handle on. For example, someone who is newly diagnosed often feels the loss of the sense that their life was predictable or under control. It's as if they had a roadmap to life and then suddenly the map is taken away from them, and it's kind of the loss of your previous sense of what the future was going to be like.

Dr. Sarah Minden: MS involves loss, loss of function, loss of hopes for one's future. Like any loss, the death of a person people grieve, they mourn, and that is a normal and healthy part of coping with and adjusting to MS. When it gets to be too prolonged or too intense and has too much of an impact on life, you know, it goes on for months and months and is causing a lot of pain and impairment, then you start to think about depression, and that is, to me, where the line begins to become clear about when you need professional help. Where friends and family and clergy aren't sufficient to help people feel better.

Dr. David Rintell: Early on in MS, individuals and families sometimes really find themselves in, I think, a state of disequilibrium or confusion because they're feeling badly about something that they hadn't really thought about having before, which was a sense of how their future was going. And in the beginning everything seems up in the air. People think, oh, can I continue to work? Can I stay living where I'm living, etc., and I would say that sometimes a short set of meetings with someone experienced helping people adapt to living with MS can be very useful. And even though this is kind of a grieving for the loss of the previous sense of what the future would be like, sometimes when you are grieving, talking to someone, whether it be a mental health professional or a clergy person or a very

wise person, but who has some experience helping people through the process of adaptation to chronic illness, that can be very useful.

Dr. Rosalind Kalb: I'm glad we're talking about grieving, because I think that has been so much a part of my work with people with MS, that there are transition points, and diagnosis is one of the first transition points where you have to start to see your life in a different way. Think of yourself maybe differently now as a person who has been diagnosed with a chronic illness, but then at transition points along the way, a new symptom that interferes with function or time to make a change in one's employment or where one's living, or there has been a relationship change, those may be times when the same kinds of grief feelings come into place. And it is important to be able to distinguish between those feelings of loss and sort of processing those feelings of loss versus depression. And I think the distinction you raised is really helpful, because grieving ebbs and flows. We go through a period of intense loss and then things start to look better and we can take steps to move forward and problem-solve and figure it out. But when one is truly depressed, there isn't that ebb and flow. One can really stay down in the dumps, and that is when you want people to recognize that is a different kind of intervention that may be needed at that point.

Dr. David Rintell: If you know someone, a mental health professional who is familiar with MS, during those difficult transitions, whether it be the initial diagnosis or a change in your work status or a change in your physical abilities, or some change in relationships, that being able to check in about those transitions with someone that you know and trust can be really valuable. Or, if there is really a change in mood or your partner is saying, "You've become so grouchy I can hardly stand you anymore," then you already know someone who has seen you before, who knew that you weren't so irritable before, with whom you could check in and explore what really is going on. Is this -- am I grieving something? Is this depression? Am I having some other kind of difficulties?

Dr. Sarah Minden: And a lot of people worry that they are burdening their friends and their family with how badly they feel, that they're talking about it all the time. And while they're probably not, to be able to have someone else to talk with this about, and sometimes talk in a way more intimately about the things that really are troubling you is a very important thing to be able to do. There is no shame in it. I mean, we are all just ordinary people here.

Dr. Rosalind Kalb: So, talking with the mental health professional is a way to be able to talk without having to worry that you are burdening your family or your friends.

Dr. Sarah Minden: That's right, yes.

Dr. David Rintell: I have had the experience, actually, with a number of men with MS, who believe that because they are men, their job is to protect their family. And then they protect their family against knowing about their own emotional state. They don't want to burden their partner or their wife or their kids with how they're feeling and, as a result, kind of bottle everything up. And they usually come to see me, those fellows come to see me because their partner or their wife has brought them in, because their emotional reactions and frustrations have begun to kind of leak out at the edges and they are becoming angry, frustrated, etc., something that is often called mood changes, where they don't seem to be the calm, understanding person they used to be. And after exploring it they'll just say, well, yeah, I don't want to burden my family with this; I should deal with it all on my own. I am trying to protect them from my anger and frustration at having a chronic illness.

Dr. Rosalind Kalb: But then those feelings leak out anyway, and so the family feels the effects and colleagues at work feel the effects.

Dr. David Rintell: Right. And sometimes --

Dr. Sarah Minden: And one of the big risks in that is alcoholism, that people try and deaden those feelings by drinking. And the very worst possible outcome is to feel that life isn't worth living and that they are burdening their family, and therefore would be better off committing suicide.

Dr. David Rintell: That is very important to highlight that. One of the questions that I ask when I know that a person is feeling badly about themselves and their mood is really bothering them, a low mood, is if they feel like their family would be better off without them. Because that is a marker for either the beginnings of or the existence of suicidal thoughts. And often they emerge -- it's a distorted thought, because we know that no family would be better off without one of their family members. But it is a reflection of feeling badly about yourself and in a way trying to protect your loved ones from what you are experiencing is just an awful, awful thing.

I always remind people that they have better felt that in the past, they can feel better in the future and, of course, their families do want them around and don't experience the burden that often the person with MS is feeling they are imposing on the family.

William Sr.: I would tell people in areas that you have problems and areas that bother you about MS, any disease, find things to replace it, to fill those voids, to replace the emptiness.

Jay and Cathy: When I get in a really low, a really low mood, "Oh, is this all there is?" And then he'll say, "Do you want to do something outside the house?" And so we'll go for a drive or we'll stop and get a hamburger or just something out of the ordinary that will break -- **Jay:** The cycle. **Cathy:** It will just break the cycle.

Cary: I generally have a reputation in our men's support group and our mixed support group for being the positive personality, the optimist, particularly when things are generally going well for me. I am trying to encourage new people in particular to be positive and proactive regarding their relationships and their disease states.

Cathy: I just think you need to persevere.

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!