



**MS Learn Online
Feature Presentation
Invisible Symptoms: Finding Support, Educating Others
Featuring Dr. Rosalind Kalb**

>>**Kate Milliken:** Welcome to MS Learn Online. I'm Kate Milliken. In our first program on invisible symptoms, we learned what these symptoms are and what we can do to manage them. We'll continue our discussion of invisible symptoms with Dr. Rosalind Kalb, Vice President of the National MS Society's Professional Resource Center.

Last time, we talked about how frustrating it can be when the people around us don't see many of the challenges that those of us with MS are living with every day. In this program, Dr. Kalb will help us with some coping mechanisms that we can use in dealing with these invisible symptoms.

Dr. Kalb, you know, when I was diagnosed in 2006, I remember, it was such a paradox in my mind of getting such a serious diagnosis from symptoms like fatigue and numbness and tingling, and I'm just curious, from your experience on whether you have a similar feeling with other patients.

>>**Rosalind Kalb:** I think that that's a very real experience for a lot of people. It's scary to get a diagnosis of MS, but you can look at yourself in the mirror, and you look the same as you did the day before you got this diagnosis, but you know that your body feels different or your mind isn't functioning the way it was, and it takes people time to figure out what that's going to mean in their lives, and how to get used to the idea that they're living with these symptoms that just aren't apparent to those around them.

>>**Kate Milliken:** I remember talking to people and saying, you know, “How are you feeling?” And me saying, “I’m not feeling well,” and I would try to kind of say things in kind of simple descriptions, well, you know, I went to bed at 8:00 and I woke up at 10:00 and I feel like I didn’t get any sleep, or I’m taking a step and I feel like there are explosions of nerves, you know, coming up my leg.

Have you found that people try to articulate what’s happening with them through kind of metaphors like that to get the impression?

>>**Rosalind Kalb:** I think that some people do that and do it very well. Some people actually need to be helped, or taught how to do that, because the symptoms are so intense for them that it becomes hard to imagine that other people can’t see it, can’t understand it, so they have to be encouraged to use descriptions like that, metaphors like that.

Somebody who is very fatigued, for example, will say “I don’t know how to describe it, except to say it’s like putting 500 pound weights on my legs and slogging through mud.”

That helps other people understand the intensity, because if you just say you’re tired, all of us feel fatigued from time to time, or we get sleepy if we’ve had a bad night or whatever, so to just say “I’m tired,” is not going to convey the extent of that MS fatigue, so people have to come up with examples to use, metaphors to use, so I think that’s very helpful.

>>**Kate Milliken:** Are there ever times that it’s a good thing, that it might be something that you don’t want to tell someone your symptoms?

>>**Rosalind Kalb:** Absolutely. If you’re in a work situation, for example, and you’re able to do your job relatively comfortably and you’re not in a position where you need to ask your employer for an accommodation in order to do your job, then the national MS society generally advises people not to disclose, so if the symptoms that you’re dealing with are invisible, and nobody’s asking questions and there’s no obvious impairment, they might choose not to discuss those symptoms at all, not to share the diagnosis until there’s a need to.

So, for those people, if they can manage those invisible symptoms comfortably, they put off whatever decision they have to make about disclosing to their employer. If those invisible symptoms, however, become so debilitating, for

example, severe fatigue, or a vision problem, or significant difficulties with bladder or bowel, then that person may need to disclose those invisible symptoms, educate their colleagues and employer about it so they can request the accommodations that they need to be effective.

>>**Kate Milliken:** In some ways, the whole concept of invisible symptoms kind of exemplifies what MS is, compared to other things that people may have. Can you relate to that?

>>**Rosalind Kalb:** Sure. I think that's why we talk about the iceberg image all the time with people with MS, that if you look at the iceberg, you see the tip of it above the water, it's very clear, those would be the visible symptoms of walking impairment or balance impairment that somebody might have, but below the surface, all the symptoms that you can't see, like that bottom of the iceberg, which is actually much bigger than what shows above the surface of the water, so I think for many people living with MS, the invisible symptoms make up the bulk of their experience of the disease from day to day. It's very, very challenging.

>>**Kate Milliken:** From your perspective, what are some coping mechanisms that people can have for certain symptoms that they may experience?

>>**Rosalind Kalb:** Well, clearly the coping mechanisms are going to differ, depending on what the symptoms are and how they interfere, but I think the very first coping mechanism is to be educated about MS and the kinds of invisible symptoms it can cause, because the first thing one has to do is make sure that you're describing all of those symptoms to your healthcare team so that they can begin to help you manage them.

I think the second thing is to know your body, so, for example, if heat causes your vision to worsen or causes your fatigue to grow, or your balance isn't as good, then that's a signal that your body is stressed or overheated, and so you learn to read those signals from your body so that you can start to do those self-care things.

I think it's also incredibly important to figure out who are the people in your life who do need to understand, the loved ones, the people closest to you? They have to know what's going on, or they don't know how to relate, and so figuring out whom to tell about the symptoms, how to describe them in a way that they can understand, or what kinds of educational materials you might want to share with them about those.

Because I think one of the things that's tricky about these invisible symptoms is that, because people can't see them, they are so easy to misinterpret. So, unless a person is educated and realizes what a common symptom is fatigue is in MS, a spouse or a child of a person who has a lot of fatigue might just misinterpret that as you're not interested, or you're too busy to do something with me, or you would prefer to do something else than do something with me.

So, when we educate people about the fatigue, it's not just me and my fatigue, this is a common symptom in MS, it makes it easier for family members to get their heads around it.

>>**Kate Milliken:** One of the things that I totally appreciate, working with a physician myself is, they do take those symptoms seriously, and I think that that type of space where they can understand, I mean, you can tell them anything and they would really listen and try to evaluate it in terms of managed care, and I think that that's been very helpful.

>>**Rosalind Kalb:** Well, and that brings up another point, and that is, one of the reasons that support groups can be so helpful is that somebody who has been dealing with invisible symptoms and nobody seems to get it, they go to a support group with other people who have MS and are dealing with similar invisible symptoms, and suddenly, they're surrounded by people who get it, and it's a feeling of total kind of acceptance, I feel normal here. I don't have to be explaining myself all the time, because when I talk about a symptom I have, I can look around the room, and people are nodding and smiling and I feel a lot of support for that.

So, that's one of the reasons that we really encourage people to find others that they can share their experiences with and connect, because it's such a feeling of validation when the rest of the world just looks puzzled.

>>**Kate Milliken:** Yeah, and I think that even if somebody doesn't have the exact same symptoms, just hearing about somebody else's MS experience, like, "Wow, that's a really weird symptom you're having. I'm not having that," but it gives you such a nice sense of perspective, which I think is really helpful.

>>**Rosalind Kalb:** So, invisible symptoms, very, very challenging, but we can do something about them, so getting people to, again, share that information with their healthcare provider and get that help would make dealing with the rest of it easier.

>>**Kate Milliken:** Understands, really, the nature of the disease. Dr. Kalb, thank you so much, and it's really nice for somebody with MS to feel such a sense of empathy from someone who doesn't have it, so thank you.

>>**Rosalind Kalb:** Thank you.

>>**Kate Milliken:** If you would like to learn more about MS symptoms or get more information on living with MS, go to www.nationalmssociety.org. This is Kate Milliken for MS Learn Online. Thank you for joining us.