



**MS Learn Online  
Feature Presentation  
Invisible Symptoms in MS  
Featuring Dr. Rosalind Kalb**

---

**>>Kate Milliken:** Hello, I'm Kate Milliken, and welcome to MS Learn Online. No two people have exactly the same MS symptoms, and each person's symptoms can change or fluctuate over time. Many of these symptoms are referred to as "invisible symptoms." In other words, no matter the challenge they pose to a person with MS, those around them are unable to see what they are coping with.

In this first of a two-part interview, we'll explore what these invisible symptoms are, and what we can do to manage them. We'll be talking to Dr. Rosalind Kalb, who is Vice President of the National MS Society's Professional Resource Center. Welcome to MS Learn Online, Dr. Kalb.

**>>Rosalind Kalb:** Thanks, Kate. It's a pleasure to be here.

**>>Kate Milliken:** Thank you. So, first and foremost, how would you define an invisible symptom, and what are they?

**>>Rosalind Kalb:** Well, I think the easiest way to think of an invisible symptom is something that if you walked into a room experiencing that symptom, the people in the room wouldn't know about it, so you might be extremely uncomfortable with pain or fatigue or foggy thinking that's just not going the way you want it to do, and nobody would know how much difficulty you were having, and there are a lot of symptoms in MS that are invisible to others.

**>>Kate Milliken:** So, can you give a range of what one might define as an invisible symptom?

>>**Rosalind Kalb:** Sure. So, if you think about it, “invisible symptom” means any symptom that’s not visibly obvious to other people. So, if you start at the top of the head and work down, cognitive changes are a very common symptom of MS. They can certainly impact a person’s quality of life, and other people around you may have no idea that you’re struggling with memory or concentration or decision-making.

You could experience significant changes in your vision, but your eyes, to anybody around you, look just as beautiful and normal as they did before, and yet you’re struggling to see the world in a steady, clear way. It’s very fatiguing, very-- has a huge impact on activities every day. Pain is a very, very common symptom in MS. It wasn’t that many years ago that people with MS were told that MS didn’t cause pain, but we know it can cause a variety of strange sensory changes, numbness, tingling, burning sensations, and severe, severe pain that affects the whole course of the day and the ability to sleep at night. Without some education, people wouldn’t even know that you were experiencing that.

Bladder and bowel changes are very common in MS, and unless somebody sees you dashing off to the bathroom in the middle of an important conversation, they might never know that you’re struggling to maintain control over bladder or bowels. All of these things take a huge amount of energy, which adds to yet another invisible symptom, which is the fatigue that’s so common in MS. So, we know that there is a unique kind of fatigue caused by MS itself, by the damage to the nerves in the central nervous system, but if you think about all of the energy it takes to cope with pain, for example, which can be so debilitating, distracting and depressing, that’s just adding on to the invisible symptom of fatigue.

And I think we also need to mention mood changes in all of this, because we know that mood changes, including depression, are very, very common in MS, both as a reaction to all these other things we’re talking about, because MS can be depressing, but also as a symptom of the disease itself, and certainly that’s not necessarily visible to friends, family and people in the workplace.

So, you know, from the top of the body down, people are experiencing things that are others can’t see.

>>**Kate Milliken:** What I'm curious about is, the fact that they're invisible, does that make them harder to treat, I mean, how are these invisible symptoms managed?

>>**Rosalind Kalb:** Well, I think that it's important to recognize that MS physicians know the range of symptoms that can appear, so if one is seeing a physician who is very familiar with MS, that doctor is likely to ask about a whole range of symptoms, but a healthcare professional who is less familiar with MS can't read a patient's mind, may not ask about all those things, so it means the people who are living with MS and have a lot of invisible symptoms need to make sure that they're alerting their healthcare professionals about all the symptoms they're having.

One of the big challenges is that people with MS don't necessarily know that a symptom they're having is related to their MS, so if they have extreme fatigue, but they don't know that that's a symptom of MS, or they're experiencing bladder or bowel changes, and it's never occurred to them that that may be related to their MS, or even pain. They don't bring it up, the physician might not ask, it doesn't get treated, so the very, very first step for people living with MS is to be educated about the kinds of symptoms it can cause, and then make sure that they communicate that to the doctor or the nurse during their regular visits.

Then, the doctor or the nurse can begin to offer various kinds of management strategies, and part of your question was, "How do we manage them?" Well, I think there's a whole range. Part of it is-- could be a medication to treat a symptom. There may also be rehabilitation strategies that have nothing to do with taking a medicine, but may have to do with exercise or using a different kind of adaptive aid to help you with something, or it may be just learning how to manage your environment and your body and take good care of yourself so that the symptom is handled, so it's kind of teamwork between a person with MS and the healthcare team to make sure they're using all the possible strategies to manage each symptom.

>>**Kate Milliken:** One of the things you hear about MS, which is true, is that it's always a very individual disease. The other thing you hear when you talk to people about MS is they say, "You know, it's so frustrating for me, because I come in, and I tell someone that I have MS, and they say, 'really, you look so great.'" This seems across the board as something MS-- people with MS actually resent in some ways. From your experience, can you articulate about that?

>>**Rosalind Kalb:** I think it's actually a major challenge for people, particularly early in the disease. You know, we all like to get compliments. Somebody says, "Gee, you look great." Well, we like to hear that, but I think sometimes, when it's a family member, or a colleague, or even your boss who is saying that, it can be a little bit of a two-edged sword. It can be paying you a compliment, or it can be also saying, "Well, I don't get it. If you look so good, how come you're not doing what I need you to do? How come you're not keeping the house clean or getting meals on the table or getting your work assignments in on time," so it requires a real educational process so that the people who are important in your life understand that what they're seeing isn't necessarily the full picture of what's going on inside you, and if you don't tell them, they're not going to know.

Nobody can read your mind, so you kind of have to put on your teaching hat and be prepared to educate all those important people in your life about what's going on that might affect how you feel on a given day, or you behave or how you perform on a given day.

>>**Kate Milliken:** I think when most people think about seeing someone who is worsening, you know, you see somebody whose limp is getting worse and you think they're progressing, or you see someone who is going blind in one eye, and you think, "Wow, that's really bad." Invisible symptoms like fatigue, in some ways, to a layman, may not seem like it's as bad.

From your perspective, being in the MS community, is it something that is taken as seriously as something that's a little bit more dramatic to see?

>>**Rosalind Kalb:** Well, I think we're always more impacted by the things that we can see, because the things that we see, we can kind of relate to and try to figure out how that would feel if it was happening to us, so, yes, I think the visible symptoms always have more impact, which is why that education piece is so important. But in terms of how symptoms affect people, there's tremendous variation from one individual to another, so for somebody who has really debilitating fatigue, they will say that is the most challenging part of their MS. They cannot get through the day and do the things that are important to them because they are so exhausted.

For somebody whose whole lifestyle depends on their physical activity level, somebody who is a ballet dancer or an athlete or repairs the roof or the TV cables,

physical impairments are devastating, because they change their whole lifestyle. For somebody for whom their ability to think and reason and problem solve is the core of the work they do, teacher or a lawyer, an accountant, then that invisible, cognitive change that is-- can be so common in MS, is the most devastating symptom, so I think the best way to think about it is, the interaction of a person's particular symptoms with their lifestyle, and they will be the best judge of which of their symptoms has the biggest impact on their quality of life and their ability to do the things that are important to them.

>>**Kate Milliken:** With all of these symptoms that we're talking about in the range of MS, how do you know that all of the symptoms actually are MS? I mean, couldn't it be possible that one of the symptoms actually isn't MS and there's something else that's wrong with you?

>>**Rosalind Kalb:** I'm really glad that you asked that, Kate, because I think it is important for people with MS to recognize that MS can cause a lot of different symptoms, so they need to know what those can be, but not to fall into the trap of assuming that everything that they experience, or everything that happens to their bodies is caused by MS.

So, once again, it's important to make sure that you mention any new or changing symptom to your healthcare team, because they can help you sort out, is this truly an MS symptom, or is there something else going on that we need to figure out?

Fatigue is a very common example of this, because we know that MS fatigue is a very common invisible symptom, but before the doctor will diagnose MS fatigue, he or she is going to look at lots of different things that can contribute to a person's fatigue. Interrupted sleep from sleep apnea, for example, is very important to identify. Sleep apnea is not caused by MS, and it's something that needs to be carefully treated, because it has other risks to it.

But it could get lost if the person living with MS assumes, "Well, I'm just tired because I have MS," so the doctor takes a very careful history of a new symptom, really tries to make sure that it's an MS symptom, and then it's not something that your general doctor really needs to be taking care of because it's a whole other health condition.

>>**Kate Milliken:** I actually have had-- lived this example, thinking that maybe I was going into a sensory relapse, because I was having such terrible tingling in my

hands, and it was going into my wrists, and my doctor said, “You know what, babe?” He didn’t say, “You know what, babe,” but he said, “You know what? I think you’ve got carpal tunnel syndrome,” and he was totally right. He did two tests and it was very clear, and that, for me, as somebody with MS, it was a huge relief.

You know, it actually-- putting in that boundary, finding out there was something else wrong was a better solution, you know, in that instance.

>>**Rosalind Kalb:** He could fix it. So, we can’t assume that everything is a direct result of MS, and it’s only by really talking symptoms over with the doctor or nurse that we can weed out those things that are MS from those that aren’t.

>>**Kate Milliken:** Thank you, Dr. Kalb, for giving us a little bit more insight into the world of invisible symptoms, which, if you have MS, you know are equally important to anything else in terms of dealing with it, so, in our next conversation, we’ll continue to learn coping techniques for these types of symptoms. We’ll see you then. This is Kate Milliken for MS Learn Online.