



**MS Learn Online  
Feature Presentation  
Sex and Intimacy  
Rosalind Kalb, PhD**

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**Tom>>** Hi, I'm Tom Kimball

**Tracey>>** And I'm Tracey Kimball. Welcome to MS Learn Online. In a recent study 63% of people with MS reported that their sexual activity had declined since their diagnosis.

**Tom>>** The reasons for this can be physical, psychological, and emotional. In today's program Dr. Rosalind Kalb, Vice President of National MS Society's Professional Resource Center openly discusses sexual problems and what can be done to reduce their impact.

**Tracey>>** As Dr. Kalb points out one of the first barriers to overcome is the lack of communication.

>>**Roz Kalb:** Surprisingly, doctors don't ask about it and people living with MS frequently don't bring it up. Sometimes they don't bring it up because they're too embarrassed; sometimes they don't bring it up because they have no idea that any change that they're experiencing could even be related to their MS. But we know that MS can affect sexual function in a variety of ways. Not everyone

experiences changes, but in the largest, best done study of this, about 73% of people reported changes in their sexual functioning.

Let me talk about the three different ways that we know of that MS can affect sexuality. We talk about primary, secondary and tertiary sexual dysfunction. The primary changes that happen are the result of actual damage in the central nervous system. So, just like any other symptom of MS, where damage to the myelin in the central nervous system causes a symptom, you can see that kind of change in sexual function.

For women, the most common changes that are caused directly by damage to the central nervous system can be a lack of interest in sex, an inability to get aroused, achieve vaginal lubrication, or to experience an orgasm. All of those are based on neurologic functioning, and when the central nervous system isn't working right, those can change.

Same way with men. Primary sexual dysfunction has to do with arousal, the ability to achieve or maintain an erection, and sometimes to have an orgasm. The other primary change that can happen to both men and women has to do with changes in sensation, so that you can experience numbness. Just like you can experience numbness in your feet or your legs, you can experience numbness in other areas of your body which can interfere with sexual pleasure. You can also experience pain. Something that used to feel good might now feel bad because of these neurologic changes.

Secondary sexual dysfunction has to do more with other symptoms of MS. "I am so fatigued, I just am not interested in having sex." "I have so much pain," or, "I have so much spasticity," or, "My bladder is out of control." Those things interfere with sex. That's secondary sexual dysfunction.

Tertiary sexual dysfunction is actually the most complex in some ways, because it has to do with all of the attitudes and feelings and

cultural messages we have about our sexuality. We live in a culture that bombards us with messages about how we should all be young, thin, healthy, sexual, and when chronic illness comes along, it really flies in the face of all those messages. And people don't know how to respond to that and it causes a lot of upset. And those ideas, those prejudices, those emotions can get in the way of sexual function, and that's the tertiary sexual dysfunction.

>>**Rick Somers:** So, worst case scenario is you could be dealing with all three levels, primary, secondary and tertiary?

>>**Roz Kalb:** Yes. I think most people most of the time are dealing with all three of those types of challenges.

>>**Rick Somers:** What are the options that people have for treating this?

>>**Roz Kalb:** Well, I think the good news is that healthcare professionals really can talk to people about this, so the good news is people should go to their doctor, should discuss any changes they are experiencing and find out what's available.

In terms of primary sexual dysfunction, again, those problems caused directly by changes to the central nervous system, there are some options. There are more for men. We've all heard about all of the pills that are now available. If you've watched any sporting event in the last five years you know that there are oral medications for men to take for sexual dysfunction. They don't work perfectly in MS, but about 50% of men with MS will get some relief from those oral medications.

There are also other forms of medications to help men with erectile dysfunction that include some injectable medications that actually work very well and are not as painful as they sound. And there are some other mechanical strategies that men can use for that.

For women, we don't have that kind of medication to treat the problems that happen with orgasm and with arousal, but women can use over-the-counter lubricants as long as they are water-based. So, a product like Astroglide or K-Y Jelly can be very helpful if a woman is not experiencing the amount of lubrication that she needs to be comfortable.

And I think that there are also therapists who can work with people who are having trouble with sexual arousal, with orgasm, to find different strategies to use. It may take more stimulation than what one has been used to needing in the past. It may also take some time to learn how your body is working and convey that to your partner, so that your relationship is growing and you're both learning about how to manage some of these primary changes.

In terms of secondary sexual dysfunction, all those symptoms we talked about of MS that can interfere with sexual activities, it's really key to talk to the healthcare team about what symptoms are getting in the way, whether it's fatigue or bladder symptoms or spasticity. Because as you address those, then the symptoms interfere less with sexual activity.

One other thing that's important about secondary sexual symptoms is that it's important for people to recognize that some of the medications they take can also interfere with sexual dysfunction. And so reviewing all the medications with your physician to make sure that any of them might be interfering with sexual function, like antidepressants, for example, which are known to have that problem sometimes, the doctor can work with a person to adjust the dosage levels and the timing of medications so they will interfere less in sexual activity.

>>**Rick Somers:** And what about the tertiary effect?

>>**Roz Kalb:** Well, I think the tertiary sexual dysfunction, as we talked about, is all those attitudes and ideas we have about our

sexuality. And that's really where the issue of intimacy comes into play and how do you maintain intimacy when you're experiencing those changes to yourself image, when you're feeling different about your own sexuality.

What's interesting about sexual dysfunction in MS and how it can affect intimacy is that for some people, intimacy is a prelude to sex. People feel intimate, they feel close, they feel warm, that leads them to feel sexual, and they engage in sex. For some people, however, sexual expression is a way to feel more intimate. So, sexuality is a very important way in which they relax and become more intimate with one another. Whichever way it is for a couple or for a person in that couple, the sexual activity is very important, and when MS interferes with it, it can have a significant impact on that couple's ability to feel intimate.

>>**Rick Somers:** And through that dysfunction sometimes it can build better intimacy.

>>**Roz Kalb:** It can, but I think communication is really key. If somebody's sexual responses change, for example, and the couple doesn't talk about it, it's very easy to misunderstand or to misinterpret what's going on. "Oh, my partner doesn't seem to be enjoying herself very much; maybe she doesn't find me attractive anymore." "My partner isn't reaching orgasm anymore; maybe I'm doing something wrong. Maybe I don't turn him on."

So, if the physical changes happen and the couple isn't able to talk about what's going on, then worries start to build up, distrust, then it becomes even harder to talk about, and suddenly intimacy is out the window.

So, the most important message is that when a person's experiencing changes, it's very important to communicate that that's what's going on, so that the partner can understand and not misinterpret any changes.

>> **Rick Somers:** So, in this sense the MS can be almost used as a strength, possibly, to bring couples closer in the sense that I disclose, you accept my disclosure, and now we're on a better page together..

>> **Roz Kalb:** I think it has the potential to bring people closer together. But, again, I think this is such a difficult and sensitive issue for people to talk about that sometimes crossing that hurdle so that they can talk and share and not misinterpret or blame is really important.

>> **Rick Somers:** What can couples do to increase their intimacy?

>> **Roz Kalb:** I'm a big advocate of talking. The problem, of course, is that sometimes these things are just hard to talk about. If you grew up in a family that never talked about sex, or sex has always come easily and smoothly in your relationship and you've never had to deal with it, it's hard for people to talk about.

Starting the conversation with a physician to get help with what's going on can start, and going to those medical visits together. Also, there are therapists who can help jumpstart these conversations, sex therapists or counselors or psychologists who have experience with chronic illness and sexuality. Sometimes it just helps to get educated and talk about it in a setting where there's a professional around to help make sure the people have an accurate understanding of what's going on.

>> **Rick Somers:** As if MS isn't difficult enough, it really -- it strips you down and it makes it raw to discuss things that, again, were possibly never brought to the forefront in conversations. And in hearing those words come out of your mouth sometimes, admitting it in front of a doctor, whether it's bowel/bladder issue, whatever it may be, when you say it, it becomes more real, and therefore you can hopefully start to tackle it a little bit better.

>> **Roz Kalb:** I think so. I think it takes a lot of courage to bring up these things. Our sexuality is a very core part of our identity and our being, and I think the most important message for individuals and couples is that this is too important a part of your life to not get help when you need it. And that by talking to each other and talking to health professionals, we can keep this part of your life on track where you want it to be.

>> **Rick Somers:** How would somebody seek out help?

>> **Roz Kalb:** I think one can start with a neurologist and ask for information and ask for referrals to specialists. And also the National MS Society can provide referrals to people who have expertise in this area. It's just taking the first step to ask. The resources are out there.

>> **Rick Somers:** And it's finding the courage to be able to ask that question.

>> **Roz Kalb:** I agree.

>> **Rick Somers:** Much like it probably was addressing your initial issues and going in and seeing a doctor to begin with. So, we've come full circle. Thank you, Dr. Kalb. We appreciate your time and your insight on intimacy.

**Tracey**>> Communication with your partner and your physician is a critical component when dealing with sexual dysfunction

**Tom**>> Indeed. To learn more click on the “resources” link to connect to the National MS Society’s program “Relationship Matters”. You can find out about classes that deal with intimacy along with a host of other topics that are critical in maintaining and nurturing your relationship with your partner.

**Tracey**>> Thanks to Dr. Rosalind Kalb and thank you for joining us today.