

# MS EMPOWERMENT SERIES

SHARED DECISION MAKING IN MULTIPLE SCLEROSIS



## SEXUALITY AND MULTIPLE SCLEROSIS

*How to Overcome Emotional and  
Physical Barriers to Intimacy*

*Where to Find Help*



An educational series for people with multiple sclerosis (MS) developed in conjunction with the International Organization of MS Nurses (IOMSN).

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## Hello, and welcome!

Sexuality is such an important issue, but it is often difficult for people with MS to discuss with healthcare providers.

We hope that the information here will provide encouragement and information. You can use it to help you initiate a discussion with your MS nurse or healthcare provider and find resources to help you.



The MS Empowerment Series was developed for the International Organization of MS Nurses (IOMSN) to provide information and resources for people with MS on topics that affect their lives. As a neurology nurse working in MS care and research for over 30 years, it's my privilege to be part of this program.

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## MS EMPOWERMENT SERIES



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## SEXUALITY AND MULTIPLE SCLEROSIS

Sexual health problems stemming from multiple sclerosis (MS) are often treatable. But many people with MS feel this topic is too embarrassing to discuss with a healthcare professional. For similar reasons, healthcare providers may feel that sexual health is too private or too personal to bring up with the patient, even if they have training and resources to treat these problems.

Kimberly Castelo, LMFT, encourages people to think about sexuality in a broader sense: in terms of closeness, connection, and the importance of human touch for healing. She speaks from experience: Not only is Ms. Castelo a licensed marriage and family therapist and certified sex therapist, she was diagnosed with MS in 2006. Working in conjunction with MS nurses and other healthcare providers, Ms. Castelo has been able to help many people with MS to improve intimacy, sexual health, and overall well-being.



# WOMEN

**37%–45% have difficulty achieving orgasm**

**36%–48% experience vaginal dryness or discomfort**

**24%–47% experience reduced sensation**

**31%–74% experience decreased libido**

## Rethinking Intimacy

“Sexuality is normal and natural. And talking to a healthcare provider can be helpful for many people with MS,” says Ms. Castelo. But she admits that this topic is often the “elephant in the room.” Many people grow up in a family environment that is silent or even shaming around the issue of sexuality, she says.

Normalizing the issue of sexuality is key to addressing problems that come up, radical acceptance of one’s own body, and understanding how to make the most of human connection. “Touch from a loving partner changes the

brain,” Ms. Castelo asserts. “Touch heals, it comforts, it soothes.” Sexuality can be thought of in terms of connection and closeness and whatever that means for that individual or couple at that moment. A “soft no,” says Ms. Castelo, might mean saying to one’s partner, “I’m too tired for the big night out we had planned, but I would like to stay home, cuddle on the couch, and talk about our day.” The most important thing, she says, is that sexual intimacy is treated as a source of comfort, healing, and encouragement—and not as a source of rejection, obligation, discouragement, or stress.

## How MS Affects Sexual Health

“When people say sexual response is all in the brain, they are partly correct,” explains MS nurse Dorothea Cassidy Pfohl, RN, BS, MSCN. Sexual arousal starts in the central nervous system. The brain conveys messages to other areas of the body, including the sexual organs. “Damage to these nerve pathways caused by MS may affect sexual response,” she says. However, this may be made worse by MS symptoms such as fatigue or spasticity, and from emotional factors such as altered body image or mood changes.

Sexual dysfunction is one of the most commonly reported symptoms associated with MS. According to a survey of people with MS cited by the National Multiple Sclerosis Society (NMSS), 63% reported that their sexual activity had declined since their diagnosis. Other surveys

suggest that as many as 91% of men and 72% of women with MS may be affected with sexual problems.

Spasticity is a symptom of MS that may interfere with libido and sexual performance. Spasticity refers to abnormal muscle firing that leads to pain, tightness, or muscle spasms. When spasticity symptoms occur, they can inhibit a person's mobility and make it hard to relax or focus. Another symptom that affects women with MS in particular is bladder control. This may cause the woman to be concerned about urine leakage during sexual activity.

"These problems can be addressed through medical interventions," Ms. Castelo says. "But many of the problems that we assume are purely 'physical' also have a large mental component," she explains. That is, we sometimes allow them to interfere with intimacy more than they really need to. Simple or creative solutions can be brought into play, once the person or couple has gotten over the idea that everything has to be perfect. For example, put a towel down on the bed to absorb any urine that might leak. Experiment with positions that minimize pain and mobility limitations. "The mental and the physical issues must be dealt with together," Ms. Castelo stresses.

This concept is particularly important for men with MS who experience erectile dysfunction (ED), she notes. Medications for ED are generally effective and are commonly prescribed

# HOW MS AFFECTS SEXUAL FUNCTION

## 40% OF PATIENTS

have concerns related to sexual health

Yet healthcare providers and patients do not bring up the subject of sexuality

## TIME CONSTRAINTS

often prevent health professionals from discussing sexuality

Pain management, mobility, bowel and bladder, depression, disease modifying therapies seen as higher priorities

Taboo

Culture, Family History

**CULTURAL BELIEFS AND NORMS LIMIT DISCUSSIONS, TREATMENT OF SEXUAL PROBLEMS**

Trauma

Misinformation

Embarrassment

Lack of knowledge



**Table. Causes of Sexual Problems Affecting People With MS**

Primary	<ul style="list-style-type: none"><li>• Nerve damage directly resulting from MS lesions</li><li>• Affects both men and women</li></ul>
Secondary	<ul style="list-style-type: none"><li>• Diminished desire or sexual response, related to effects of MS such as pain or spasticity</li></ul>
Tertiary	<ul style="list-style-type: none"><li>• Psychosocial changes due to depression or change in body image</li><li>• Body image sexual dysfunction affects about 28% of women and 14% of men with MS</li></ul>

to treat male sexual dysfunction. But they can also lead the man to feel that he is at fault if the medication fails to work at times. This is likely to occur for men with or without MS. “This is why it is also important to acknowledge the emotional and mental side of arousal,” Ms. Castelo says, instead of expecting the medication to do all the work.

Depression is a major contributor to problems among couples and sex-related problems, whether or not the person has MS. The depressed person may just feel like being alone and avoid any interaction. Ms. Castelo advises that touch—a gentle hug, a comforting hand

to hold—can be healing and may be the small step that an individual needs as a way to re-connect. Depression requires treatment by a professional. Intimacy issues can and should be a part of that discussion, Ms. Castelo suggests. Sexual health is tied in closely with self-esteem, feeling valued and wanted, and many other issues that affect mood.

### **Talking to Your MS Nurse or MS Care Provider**

When discussing MS symptoms with a care provider such as an MS nurse, it may help to explain how that symptom interferes with your usual activities. In the same manner, discussing sexual problems or asking questions about sex-

**MEN**

- up to 75% have difficulty obtaining and maintaining erection**
- 18%–50% experience difficulty ejaculating**
- 37% experience difficulty achieving orgasm**
- 39% experience decreased libido**

The infographic features a background of a grey brick wall. On the left side, there is a partial view of a man sitting on the ground, looking down. The text is overlaid in white, bold, sans-serif font.

uality can be part of that discussion. Even if it seems awkward, especially with a provider you don't know well, you should remember that this person has probably treated dozens or even hundreds of people who have asked this same question. Finding the right professional to talk with is key. If the health professional you usually interact with does not have the resources, there may be another person in the practice, or in the community, to whom your MS nurse can direct you.



Some questions that a person with MS might ask that would help initiate the discussion could include:

- I have noticed that my MS has had an effect on my sexual health. Can we discuss some of those issues?
- Some of the issues that affect me are: changes in physical sensation or sexual response, vaginal dryness or numbness, erectile difficulties
- I have bladder/bowel problems. What are some ways to manage this and still have a healthy sex life (or, still be intimate with my spouse/partner)?
- Can you tell me if this medication has any sexual side effects? (Many antidepressant medications cause changes in libido or low sex drive.)
- I (or my spouse) have had difficulty with intimacy since my diagnosis. Can you refer us to someone who can help?

### **What a Couples Therapist or Sex Therapist Can Do**

A professional therapist can help an individual to work through body image and self-esteem problems that often accompany a diagnosis of MS, Ms. Castelo suggests. "The first step is body acceptance," she says. "It's important that we radically accept the body that we are in right now. No matter who we are, or what challenges we face, we are still deserving and worthy of being loved, touched, and accepted."

## Q&A

### With an Expert on Sexuality and MS



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University, Bronx, NY  
Director of Neuropsychology  
and Psychosocial Research, Holy  
Name Medical Center Multiple  
Sclerosis Center, Teaneck, NJ

**Q: Damage to nerves from MS can decrease a person's ability to feel stimulated sexually. Does this happen to every person with MS, or only some people?**

**A:** Nerve damage directly related to MS may affect as many as 75% of people with this disease. These changes can happen early in the disease course and in people who have relatively little disability from MS. For most people, there are multiple causes which may be *primary* (related directly to MS nerve damage) or due to other factors such as MS symptoms or psychosocial issues (see Table, page 8). Although sexual problems are common, we also know there are treatments for these problems.

**Q: Which symptoms of MS tend to affect sexual function the most?**

**A:** The MS symptoms that seem to have the greatest impact on sexual function are depression and bowel or bladder dysfunction. Another common problem is due to medications that can interfere with sexual functioning—usually not disease-modifying

therapies, but some symptomatic treatments used in MS.

Our research group has developed a screening tool called the MS Intimacy and Sexuality Questionnaire. This can be used to better understand the impact of MS on intimacy and sexuality. A healthcare professional goes through a checklist of common symptoms and concerns and asks the person with MS how much each one interferes with sexual functioning. This can help to determine the best treatment approach.

**Q: What hopeful information can you offer for people with MS who are concerned about the effect of the disease on their sexual health?**

**A:** Problems with sexual function that affect people with MS are largely treatable. This often means aggressively treating MS symptoms that may be involved. For both men and women, we have to address the specific causes and treat those issues. Men may experience erectile dysfunction, but there are now multiple ways to treat that condition. If depression is part of the cause, appropriate treatment will often resolve some sexual problems. If painful spasms are causing problems, aggressively treating that symptom frequently results in improved sexual function. Counseling may be useful to help the person adapt sexual behaviors or resolve problems related to body image. By looking into underlying causes, aggressive symptomatic management, and providing counseling, almost everyone with MS-related sexual dysfunction can be helped.

And it's okay for us to give love and acceptance to someone else." This is not easy, especially in a society that feeds us unrealistic images of attractiveness and what it means to have a healthy sex life.

For couples, working with a certified sex therapist or couples therapist can be valuable and even life-changing, she says. Finances may be an issue, since many do not accept insurance plans, but she says that many of her patients receive reimbursement for treatment with out-of-network benefits. For some, the therapy sessions may not need to go on indefinitely.

The therapist may be able to point out communication barriers, or suggest games or exercises to open up the conversation.

For a person who is single or not in a committed relationship, other issues arise. Do you reveal that you have MS to a prospective partner? Or keep it to yourself? It's important to remember that MS does not define an individual or dominate that person's life. Rather than seeing yourself as "a person with MS," identify with other traits about yourself that you like or aspire to: your current or future career, a hobby you're passionate about, a future goal.

## RESOURCES

### Organizations

- American Association of Sexuality Educators, Counselors, and Therapists (AASECT), [www.AASECT.org](http://www.AASECT.org)  
202-449-1099
- National Multiple Sclerosis Society  
[www.NationalMSSociety.org](http://www.NationalMSSociety.org).

### Books

- *The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain, and Illness*, by Miriam Kaufman, MD, Corey Silverberg, and Fran Odette. (Available on Amazon.com)
- *Love Sense and Hold Me Tight, Seven Conversations for a Lifetime of Love*, both by psychologist Sue Johnson.  
<https://www.drSueJohnson.com>

### Magazine

- National MS Society. MS in Focus: Intimacy and Sexuality (28-page magazine)  
[www.nationalmssociety.org](http://www.nationalmssociety.org)  
(Search "Intimacy and Sexuality pdf")

### Video and other resources

- Sex Ed for Grownups: Intimacy in MS  
[www.nationalmssociety.org](http://www.nationalmssociety.org)  
(Search "Sex Ed for Grownups")
- MS International Federation  
[www.MSIF.org](http://www.MSIF.org) (Search "Let's talk about sex and MS")

### LiveWise MS

Check out this site for more on how physical fitness affects cognition, [www.livewisems.org](http://www.livewisems.org)

### Screening Questionnaire

Multiple Sclerosis Intimacy and Sexuality Questionnaire (MSISQ-19). <https://www.med-iq.com/files/noncme/material/pdfs/MSISQ-191.pdf>





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