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SPECIAL SECTION

How to reclaim intimacy

PLUS, MORE ON STRENGTHENING YOUR RELATIONSHIP



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momentum

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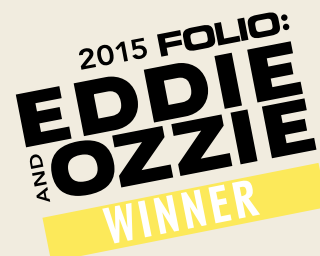
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Get closer

by Aviva Patz

How to reclaim intimacy with your partner

Kellen Prouse, who has MS, and his wife, Meghann, have found new ways to show affection for each other.

PHOTO BY MEGHANN PROUSE

Kellen Prouse never thought that at age 31 he'd have to worry about his performance in bed. But six years after his diagnosis with multiple sclerosis, he finds that his body doesn't always cooperate. "The biggest thing is maintaining an erection," says Prouse, of Bremerton, Washington, who has a progressive form of the disease. "I have a lot of numbness from the neck down, so it's not like I don't have **any** feeling, but it's not what it used to be."

Laura Wolff, of Ferguson, Missouri, believes that taking two to three times as long to reach orgasm was probably the first sign of her MS, though she didn't know it at the time. "During that first summer after my diagnosis in May 2010, I was falling apart so quickly and I was in so much pain that when we did have sex, I just cried," she says.

Stories like these play out in the bedrooms of an estimated 75 percent of people with the disease. "MS typically affects every part of someone's life, including their sexual functioning, sexual identity and their intimate sexual relationships," explains psychologist Linda Mona, PhD, president of Inclusivity Clinical Consulting Services, which provides psychological services to clients and trains healthcare providers on sexual health and disability. Many people choose not to discuss their sex life—let alone the physical, emotional and cognitive problems they may be experiencing with it—because they're embarrassed or because they don't realize that it's related to their MS.

But intimacy and sexuality are core components of the human experience. "Just because you have MS doesn't mean it's the end of your sex life or that you and your partner can't enjoy sex," says Stanley Ducharme, PhD, a clinical psychologist and sex therapist at Boston Medical Center and professor of urology at Boston University School of Medicine. "You just may have to get more creative, talk about things that are difficult to talk about, try new things that haven't been part of your sexual repertoire, and understand that sex may not happen the same way it did before."

Read on to learn more about sex challenges that can occur due to MS—and how you can work around them to reclaim the closeness you deserve.

In the bedroom

MS interferes with intimacy in a number of ways. First, there are physiological changes that go along with the disease, known as primary factors. At their root is the same issue that's behind most other MS symptoms: miscommunication between the brain and the body.

"Normally the brain sends arousal messages to the sexual organs along the nerve pathways in the spinal cord," Dr. Mona explains. "In MS, because of damage to the nerve pathways, those messages don't get transmitted—basically there's a disconnect between the brain and the genitals."

Some 70 to 90 percent of men will develop male sexual dysfunction (MSD), according to **Sex Ed**

for Grownups: MS in Intimacy

an archived webinar available from the National MS Society. The most common problem is erectile dysfunction, but men may also experience altered genital sensation (numbness, pain, increased sensitivity), a delay or inability to achieve orgasm, and a delay or inability to ejaculate. "Orgasm and ejaculation are two different processes," Dr. Mona notes. "You can have one without the other."

Some 40 to 70 percent of women also experience sexual dysfunction. The most common problem is low desire, accompanied by problems with lubrication, lack of sensation, difficulties with arousal, difficulties reaching orgasm and sexual pain. "I don't have orgasms a lot because it's work and it takes time," says Wolff. Whereas climaxing used to take her five to eight minutes with stimulation from her partner, it now takes 20-plus minutes and now requires the help of a high-powered, plug-in vibrator.

Compounding the sexual issues are other symptoms of MS, known as secondary factors: Fatigue can suppress sexual desire; spasticity can affect sexual positioning; and physical pain can sabotage both.

Then there are out-of-control bladder and bowel symptoms. "It's hard to be intimate when you're in so much pain and so many things are not working," says Wolff, who's been married to her husband nearly 30 years.



For more on this topic, download the National MS Society brochure, Intimacy and Sexuality in MS, at nationalMSSociety.org/sexuality.

The emotional side

It's easy for people who have dysfunction to start feeling down on themselves. Enter the tertiary factors. "They may feel inadequate, worried that their partner no longer finds them attractive, afraid of rejection, ashamed of how their body looks and uncomfortable with their partner seeing them naked, so they shy away from being intimate," Dr. Ducharme says. "All of that can contribute to feelings of depression and a cycle of negative thinking."

Prouse has definitely felt his confidence dip at times. "In the beginning it was tough to cope with moments when things didn't cooperate or go to completion," he says. "I've gone through feelings of inadequacy, the idea that I'm letting my wife down, all that."

The problem can be particularly acute for people whose self-esteem is closely tied to their sexual performance. Walker Thornton, 61, of Charlottesville, Virginia, learned this over time as the primary care partner for her ex-husband, who had MS. "One of the biggest challenges for me was my husband's reluctance to talk about his emotions or the challenges he faced sexually," says Thornton, who was studying to be a sex educator at the time and who now writes at **WalkerThornton.com**. "I could see his frustration, but I don't think I fully understood the feeling that his masculinity was being affected by the loss of sensation in his lower body."

Thornton's experience speaks to another big obstacle here—the care partner role, which can make the

partnership feel out of whack. "It's hard for people to bounce back and forth from being a care partner—helping with bladder and bowel issues and emptying the commode—to being a lover," Dr. Ducharme says. Shifting jobs and responsibilities in the relationship can also take a toll. When one partner has to pick up the slack for the other, he or she may begin to feel unduly burdened and resentful, which can erode a sense of partnership and threaten intimacy. But all of these issues can be addressed.



PHOTO COURTESY OF THE NATIONAL MS SOCIETY

Anquette, diagnosed with MS in 2013, with her husband in Detroit. Exploring new kinds of physical contact can help people maintain romance when MS gets in the way.

Treatments for erectile dysfunction in men include:

- **Medications to increase blood flow to the penis.** These include Viagra® (sildenafil citrate), Levitra® (vardenafil), Stendra® (avanafil) and Cialis® (tadalafil). Most men have only mild side effects from these medications, but these can include vision changes, flushing, headache, upset stomach, stuffy or runny nose, back pain and muscle aches. These medications all work in a similar manner but differ in how they are taken, how long they take to begin working and how long they last. However, all these medications can cause an unsafe drop in blood pressure, and many of them should not be taken by people who also take certain heart medications or certain recreational drugs, such as amyl nitrate and butyl nitrate, which are sometimes known

as "poppers." It's important to discuss the side effects and risks with your doctor before starting one of these treatments.

- **Penile vacuum pumps**, to increase blood flow mechanically.
- **Injections of papaverine**, a vasodilator, into the penile shaft, which causes blood vessels to expand, allowing more blood to enter the penis.
- **MUSE (alprostadil) urethral suppository**, a medicine that's inserted with an applicator directly into the urethra (penile opening), stimulating erectile tissue, enlarging arteries for greater blood supply, and preventing blood from leaving the penis for a maintained erection.

Treatments for women's sexual dysfunction include:

- **Addyi™ (flibanserin)** is a newly FDA-approved female libido-booster. Unlike Viagra, which brings blood flow to the genitals, Addyi works in the brain, boosting the release of the pleasure hormones dopamine and norepinephrine and tamping down serotonin, which can decrease sexual interest and pleasure if released in the wrong place at the wrong time. Common side effects, though usually mild, include dizziness, sleepiness, nausea, fatigue, insomnia and dry mouth. Other possible side effects include

anxiety, constipation, abdominal pain, menstrual spotting, rash, sedation and spinning sensation (vertigo).

- **Clitoral pumps**, which suction around the clitoris, assist with vaginal arousal. A new one is Fiera, a wearable intimacy enhancer that uses suction and stimulation to increase blood flow and lubrication. It's meant to be used 5 to 15 minutes before sexual activity.
- **Vaginal lubricants**, which can reduce dryness and increase pleasure.

Seeking medical treatment

Before you even begin to solve any problems in the bedroom, it's important to first address other MS symptoms that could be getting in the way. Work with your healthcare team to manage symptoms—whether physical, cognitive or emotional—that may interfere with your shared activities or physical intimacy.

For example, Wolff didn't feel comfortable being intimate until she had her bladder issues under control. "All I ever felt was my bladder—it was an overwhelming

thing," she says. Then she got Botox® injections (a treatment for incontinence) and started using a catheter. "Getting that addressed really freed up the possibility of feeling other sensations again," she says.

The good news is that there are many therapies—both medications and devices—that can help once you raise the subject with your healthcare team. "Physicians and psychologists work most directly with the body-mind changes affecting sexuality and MS," Dr. Mona says, "but the entire interdisciplinary team should be ready

to address sexuality with their patients.” And if they can’t, all hospital facilities should have a sexuality resource team member who can triage questions for patients.

Most people feel comfortable talking first with the provider to whom they’re closest, or to their primary care physician. If you’re anxious about starting the conversation, Dr. Mona recommends openers such as, “I have questions about how my MS might be affecting my sexuality,” or, “I don’t know how to talk about my MS to a new person that I’m dating. Who can I talk to about it?” Then there’s the no-nonsense approach: “Can we talk about sex?”

Not all treatments are successful for everyone, and you may need to work with your physician to find the right one for you. In addition, if your sexual challenges are related to pain, spasticity, numbness or other symptoms of MS, these will likely be treated with medications that aren’t specific to sexuality.

Becoming creative

Even more important than changing what’s happening in your body may be changing what’s happening in your mind. “It’s so ingrained in us that sex needs to include intercourse, so people automatically think **that**, instead of just enjoying being naked with their partner, touching, caressing and even mutual masturbation,” Dr. Ducharme says. As long as you cling to a traditional or narrow definition of sex—for example, penetration with ejaculation for heterosexual couples—and as long as there are problems with those functions, you’re setting yourselves up for failure and disappointment.



Kellen and Meghann Prouse have a sense of humor regarding their intimacy, which takes the pressure off the need to perform. Expanding the definition of sex is important when there are physical limitations, experts say.

PHOTO BY MEGHANN PROUSE

Instead, Dr. Ducharme suggests thinking of sex in a new way, “with more of a focus on kissing, hugging, caressing, using your mouth, using parts of the body where there’s more sensation.” He advises spending more time on foreplay, as it might take longer to get aroused, have an erection and reach orgasm. And if you can’t do those things, he adds, enjoy what you **can** do—like massage and touching.

Dr. Mona suggests actively expanding your sexual repertoire—by exploring sexual positions that are more comfortable, using sexual enhancement products like

“Just because you have MS doesn’t mean it’s the end of your sex life or that you and your partner can’t enjoy sex. You just may have to get more creative, talk about things that are difficult to talk about ... and understand that sex may not happen the same way it did before.”

—Stanley Ducharme, PhD

vibrators to help with arousal, and just being open to different ways of making love. “I truly believe that people living with chronic health issues become the ultimate creative lovers,” she says. “Physical differences and limitations force people to think more broadly about their sexual activity options and expand their repertoire of skills, fantasies and sexual possibilities.”

Prouse and his wife of nine years have tried sex toys, but that’s ultimately not what sustains their sex life. “It’s fun, but that’s not really what it’s about for us anymore,” he says. “We’re not trying to replace what we’ve lost; we’ve adapted as sexual partners.” Instead of feeling pressure to perform, Prouse and his wife take their sweet time when things heat up, allowing both partners plenty of time to get aroused, laughing together all along the way. Outside the bedroom, they spend a lot of time holding hands and cuddling. “There are other ways to show you love someone than with your genitals,” he says.

Hugging and kissing keep Wolff and her husband intimate day to day. “Compared to other people, we hug a lot,” she says. And they manage to have sex a lot, too—three to four times a week on average, because they believe it’s important. “It’s like Greg is on my schedule,” Laura says. “Eating right and exercise have to be on my schedule because both of those things are crucial to my health. Intimacy needs to be on my schedule in the same way.”

Apart from getting her bladder issues under control, the secret to their success has been finding optimal timing. “It changed a lot when we switched to mornings, after the kids would leave for school,” she says. “We had energy, we weren’t tired, it was a gift.”

Although it still takes effort, Wolff values the intimacy it affords. “I have fatigue, I have pain, I have a laundry list of complaints, but I can still have a really nice moment with my partner,” she says. “It’s important even if it’s not intercourse—it could be back rubs or touching. It makes you a team.”

Beyond sex

Some of the most powerful ways to feel intimate have nothing to do with sex. “Communication is No. 1,” says Dr. Ducharme. “You need to be able to talk honestly with each other and address issues as they arise rather than keeping things bottled up and getting resentful.” Intimacy is, after all, about emotional closeness, which involves trust and respect, shared values and expectations, and a balanced give-and-take.

To address the imbalance that happens inevitably when one person is the care partner, Ducharme recommends hiring a personal care assistant to manage bladder and bowel needs, if finances allow, to remove the partner from that aspect of caregiving. If that’s not in the budget, focus on trying to make sure both partners are still giving and receiving in some way, even if they’re no longer taking out the garbage or changing the sheets.

Whether you’re doing more than your fair share of giving or receiving—or you have other concerns weighing you down—consider opening up to your partner about your feelings or frustrations or problems you’d like to solve. It helps to frame your thoughts in a positive way: “I’d really like us to try X,” instead of, “I’m unhappy that we never do X.”

Of course that’s easier said than done. “People living with MS and their partners are likely to have many different feelings about themselves and their relationships,” Dr. Mona says, which is why you might want to find a therapist who can help you sort through them. “Communication about relationships is difficult enough, and when you add sex to the conversation, it gets even harder.” She adds, “But talk, talk, talk and keep talking—your relationship is worth it.” ■

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Care to comment? Email us at editor@nmss.org.