

# Intimacy and Sexuality in MS

A satisfying, intimate relationship rests on a broad foundation of trust, open and honest communication, shared goals and expectations, and mutual respect and concern. MS can affect intimacy between partners by bringing about changes in the roles and responsibilities in the relationship; disrupting people’s plans and expectations for the future; changing sexual feelings and responses; and making it harder to share uncomfortable feelings and fears.

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## THE CHALLENGES TO INTIMACY

### MS is like a “third wheel”

For many couples, MS becomes like a third wheel in their relationship – an annoying presence that is always getting in the way. Make sure that you and your partner are working together to adjust and adapt while making sure that your feelings of frustration are directed at the MS rather than each other.

### MS changes the “rules”

When shared expectations and dreams are threatened by a chronic illness, partners need to identify ways that will allow them to pursue their shared goals and avoid blame and guilt. Creativity, flexibility, and a good sense of humour seem to be the key ingredients for making things work when life hands you something other than what you bargained for.

### MS introduces uncertainty into everyday life

No one can predict how MS is going to behave from morning to afternoon, let alone from one month or year to the next. Partners can maintain a greater feeling of control by engaging in some joint planning and problem solving – whether it’s a back-up plan for tomorrow’s family outing or financial planning for the future.

### A chronic disease strains resources

MS can eat up more than its share of a couple’s valuable resources, including money, emotional energy, and time. When MS is allowed to strain the existing resources, people can be left feeling overwhelmed, drained, and resentful, particularly if other important needs go unmet. An intimate partnership thrives best when both partners’ needs are recognized and resources are shared.

### MS can interfere with roles and responsibilities

In long-term relationships, partners tend to split up the jobs and responsibilities that keep everyday life on track. When MS makes it difficult or impossible for one partner to carry out some of his or her responsibilities, the other partner may need to pick up the slack. The trick to maintaining balance in a partnership is to make sure that responsibilities are swapped in such a way that both partners remain on the giving and the receiving end of things.

## MS can make open communication more difficult

Talking about tough issues is never easy, and MS-related challenges are no exception. Finding ways to talk openly is the first step toward effective problem-solving and the feelings of closeness that come from good teamwork. Couples counseling is an ideal setting for starting some of these difficult conversations.

## MS can interfere directly and indirectly with sexual function

Although study results vary somewhat, the data indicates that people with MS report problems with sex more often than people who don't have MS. Fortunately, there are many sources of help and support. Your doctor can usually start the process of identifying the source of problems and offer both medical and non-medical treatment options and/or referrals to specialists.

## UNDERSTANDING HOW MS CAN AFFECT SEXUAL FUNCTION

MS can affect sexual feelings and functions both directly (referred to as primary sexual effects) and indirectly (referred to as secondary and tertiary sexual effects).

### Primary sexual effects

The central nervous system (CNS) makes sexual arousal possible; the brain, sexual organs, and other parts of the body send messages to each other along nerves that run through the spinal cord. Just as with other aspects of MS, sexual problems can arise at any time, without any clear cause. The primary sexual effects, which occur as a direct result of demyelination in the spinal cord or brain, include:

- Decreased or absent sex drive.

- Altered genital sensations such as numbness, pain, or hypersensitivity.
- Decreased vaginal muscle tone.
- Difficulty or inability to achieve an erection.
- Decreased vaginal lubrication and clitoral engorgement.
- Difficulty with or inability to ejaculate.
- Decreased frequency and/or intensity of orgasms.

### Secondary sexual effects

In addition to the changes caused directly by damage to the nerve fibres in the CNS, secondary problems can arise as a result of other MS symptoms or the medications used to treat those symptoms. The most troublesome symptoms include fatigue, spasticity, bladder or bowel problems, sensory changes, decreased non-genital muscle tone, cognitive impairments, tremor, and pain.

### Tertiary sexual effects

The tertiary effects on sexual feelings and responses result from psychological, social, and cultural attitudes and issues. Tertiary effects can affect both partners and may include performance anxiety and changes in self-esteem; depression, demoralization, and guilt; and family and social role changes.

## MANAGING SEXUAL PROBLEMS

### 1 Talk about it

Often the biggest problem is the inability to discuss sex and intimacy with one's partner. Learning to talk more comfortably about sexual issues is a process. Writing down your thoughts may help put the problems into language and start the difficult process of communicating.

Also, telling your partner what feels good and what doesn't becomes crucial to intimate relations when MS changes the body and the mind. It's equally important to find out what your partner wants, particularly if the intimate activities you've previously enjoyed are no longer possible. Confiding in your partner deepens intimacy and may go a long way toward resolving fears.

### 2 Talking to your health-care team

An easy way to begin the conversation with your doctor is by requesting regular checkups related to sexual health: Women should request annual breast and pelvic exams, and after age 40, regular mammograms. Men should have regular testicular cancer screening and an annual prostate exam after age 40. Many sexual problems associated with MS can be medically managed, but your doctor isn't likely to focus on ways to minimize the effects of MS and MS treatments on your sex life if you don't ask.

### 3 Identifying treatment strategies

There is no single site for sexual response in the human nervous system. The nerves that orchestrate it are spread throughout the brain and spinal cord. This means that there are many pathways where MS lesions might disrupt nerve messages for sexual activities or feelings. Figuring out exactly what is causing the problems you're experiencing may take some detective work and patience. Your neurologist or doctor may consult with or refer you to other specialists, including a psychologist, urologist, and/or gynecologist.

## MANAGING PRIMARY SEXUAL PROBLEMS – WOMEN

### Loss of sex drive

Currently, there is no proven medical treatment for loss of sex drive (or libido) in women. Sometimes the sex drive simply returns. Other times the loss or lessening of intensity may be permanent. Demyelination, fatigue, anxiety, decreased self-esteem and/or depression can all cause loss of desire. Women can experience sexual pleasure even in the absence of a powerful drive.

### Sensory changes

Sensory changes like numbness, which sometimes occur in the vaginal area, can make intercourse uncomfortable or interfere with orgasm. Gently rubbing the genital area with a gel cold pack or a bag of frozen peas can also reduce discomfort. Increasing stimulation to the genital area can help overcome numbness. In some cases, oral or manual stimulation of the clitoris will be enough to enable a woman to achieve orgasm. If this is not sufficient, vibrators and other sex toys may provide even greater stimulation.

### Decreased vaginal lubrication

Decreased lubrication makes intercourse uncomfortable. Water-soluble lubricants are an easy solution. Over-the-counter brands such as K-Y Liquid® and Astroglide® are widely available. Avoid oil-based lubricants like petroleum jelly because they can trap bacteria and cause infections.

## Muscle weakness in the vaginal area

Kegel exercises can strengthen the muscles in the vagina, which may enhance sensation and sexual response. To locate these muscles, try to stop the flow of urine as you urinate. Once the muscle is located, contract it a couple of dozen times a day, independent of urination. Except for the test, don't contract during urination as this may cause a pattern of incomplete emptying, leading to infection.

## MANAGING PRIMARY SEXUAL PROBLEMS – MEN

### Erectile problems

In some cases it may be hard to tell what is causing the erectile difficulties. Demyelination may directly affect erectile function. Medications may also be factors. Stress and anxiety produced by living with MS may contribute to or even be the primary cause of erectile dysfunction. Your doctor will try to clarify the source of the problem in order to choose the most appropriate solution. Currently, there are three oral medications – Viagra<sup>®</sup>, Cialis<sup>®</sup>, and Levitra<sup>®</sup> – that can be used to treat erectile problems. All three drugs work by allowing an erection to occur when a man is adequately stimulated; they do not produce an erection in the absence of stimulation. Before taking any one of these drugs, it's important to take precautions against possible drug interactions and to discuss side effects with a knowledgeable doctor. Men who have heart or blood pressure conditions or who take nitrate-based medications may be especially at risk for problems.

Other medication options include self-injection of papaverine or Prostin VR<sup>®</sup> into the spongy tissue of the penis. Most men report excellent results with this relatively painless injection that produces an erection without any stimulation being necessary.

## Other options are also available

The vacuum tube and band device can be an effective alternative to medications. It consists of a plastic tube that fits over the penis with a pump and band for the base of the penis. The hand pump produces vacuum pressure, and the band constricts the veins. This makes the penis fill up with blood, producing an erection. The tube is then removed. Because of its effectiveness and availability, the vacuum tube and band are widely used by men with MS. The tube and band device can be purchased in specialty shops and through mail-order and Internet catalogs. Catalogs and specialty stores also sell rubber rings to be worn at the base of the penis. These rings reduce blood flow out of the penis and can help to maintain erections. It is important to get instruction on using such devices from a urologist or other medical professional to prevent damage to the penis.

## Decreased genital sensation

Sensory changes in the genital area may impair pleasure or interfere with ejaculation. Manual and/or oral stimulation may provide enough extra sensory input for erection and orgasm.

## Ejaculation problems

Some men with MS may be unable to ejaculate. Others may experience what is known as a "retrograde" or backward ejaculation, in which the ejaculate travels back up into the body. Although this problem is not harmful in any way, it can interfere with efforts to conceive a child. Men who are unable to ejaculate can be given medication or other treatment to stimulate the process.

## ADDRESSING PROBLEMS EXPERIENCED BY MEN AND WOMEN

A variety of strategies are available for managing the primary sexual problems that are common to women and men:

### Achieving orgasm

People tend to think of orgasm as the ultimate goal of sex – but this doesn't have to be true. In other words, sex can make people feel good, even when it doesn't lead to orgasm. Temporary or even permanent loss of orgasm does not invalidate a man or woman's need for intimacy and sexuality. Making love does not necessarily mean having intercourse.

### Redefining sexuality

Men and women with MS may want to redefine sexuality for themselves. This may mean putting more emphasis on forms of touching that provide warmth: cuddling, caressing, and massage, for example. Some may need to explore sexual activities that require less mobility. Many people are uncomfortable with the idea of masturbation. The fact is most sex experts today say that solo sexual activities help people to redefine and renegotiate their sexuality.

### Rediscovering one's body

Certain MS symptoms cause the body to respond very differently than it once did. Body mapping is a simple exercise in self-exploration. The idea is to map out personal sensations by touching yourself from head to toe. Mapping will help identify areas of change, numbness, discomfort and pleasure. More advanced body mapping exercises include both partners.

## MANAGING SECONDARY SEXUAL PROBLEMS

Many sexual problems produced by MS symptoms (such as pain, spasticity and fatigue) or MS treatments (such as a catheter or medication side effects) can be managed with the help of your doctor.

## ADDRESSING TERTIARY PROBLEMS

### Feeling sexy

Being sexy has a lot to do with feeling sexy. Take care of your body through healthy food, relaxation, and enjoyable exercise.

### Thinking sexy

What things are sexually exciting to you? What things are turn-offs? What thoughts interfere with or suppress your sexuality? Self-scrutiny is an important part of maintaining sexuality in your life, especially if MS has dampened desire. Thinking more positively will help to restore enthusiasm.

### Enhancing romance

Find ways to transform the everyday into the romantic. Dine by firelight, take a bath by candlelight, watch the sun set or the moon rise, hold hands or flirt. Most important of all, don't give up the pleasures of physical and emotional intimacy

## CAREGIVING AND SEXUALITY

It is important for the well partner to maintain some regular personal time away from caregiving duties because that helps prevent feelings of resentment. It may also be important for the couple to create new rituals and new sexual signals that separate caregiving activities from sex and romance.

## Further Reading (English Only) – request French book listing

The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain, and Illness (2nd ed.) by Miriam Kaufman, M.D., Cory Silverberg and Fran Odette, Cleis Press, 2007. This publication can be ordered from [www.indigo.ca](http://www.indigo.ca) or your local bookstore.

Enabling Romance: A Guide to Love, Sex, and Relationships for People with Disabilities by Ken Kroll and Erica Levy Klein, No Limits Communications, 2001. This publication can be ordered from [www.indigo.ca](http://www.indigo.ca) or your local bookstore.

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## How to reach us

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