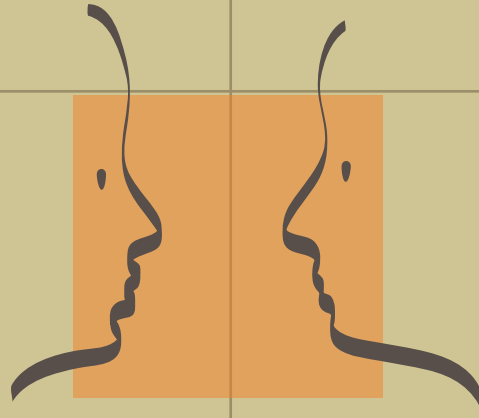




National  
Multiple Sclerosis  
Society

*Talking with Your  
MS Patients about  
Difficult Topics*



Talking about  
Sexual  
Dysfunction

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*Professional Resource Center*

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The National MS Society's Professional Resource Center (PRC) has long been a resource for health professionals providing care to people with multiple sclerosis. The PRC, which houses a comprehensive library of MS information, provides continuing education opportunities and offers multidisciplinary expertise on MS disease process and management questions, health insurance issues, long-term care options, and the development of MS specialty clinics. The goal of these services is to enhance quality of care and increase access to care for people with multiple sclerosis.

Physicians are invited to consult via email with MS specialist colleagues who serve on our National Clinical Advisory Board

**MD\_info@nmss.org**

Allied health professionals are invited to consult via email with MS specialist colleagues

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## Introduction

This booklet is designed to facilitate conversations with your patients about MS-related sexual changes and recommended treatment strategies. Sexuality is difficult for most people to discuss—even with their physicians. In addition, many people with MS are unaware

that sexual dysfunction can be related to the disease. The following are strategies for addressing this sensitive topic in ways that will reduce embarrassment and foster comfort and communication between you and your patients, and between your patients and their partners.

### 1. How and when should I address the topic of sexual problems in MS?

- Since changes in sexual function and/or responsiveness are common in MS, and can occur even as an early symptom of the disease, it is important to raise this issue beginning at the time of diagnosis. You are encouraged to include sexual problems in your initial discussion of possible MS symptoms, and revisit this subject as often as necessary.
- By talking openly about possible sexual changes, you are alerting your patients to potential problems and simultaneously giving them the message that you are comfortable discussing the topic and prepared to provide treatment or an appropriate referral if the need arises.
- Questions about sexual function should be included in your initial evaluation and during subsequent office visits, particularly if there has been significant disease activity, a change in bowel and/or bladder function, or a change in the medications you are prescribing. If you conduct a review of systems during your initial and/or follow-up evaluations, asking about sexual function when you are inquiring about urological or gynecological function provides a context that facilitates discussion. If you use a patient self-report for this purpose, include a question on sexual function.
- Patients and their partners benefit from this information because it helps to forestall miscommunication, misunderstanding, and hurt feelings in the event that these changes occur. Open discussion also provides people with a vocabulary for talking about this difficult topic.
- It is important to address the topic of sexual function even with patients who are single or have no apparent partner. Single people and gay or lesbian patients who do not bring their partners with them to the doctor's office, may find it particularly difficult to raise the topic of sexual changes. They also resent any assumption on the part of their healthcare providers that they have no sexual interest or concerns.

### 2. How can I convey this information in a way that protects my patients' self-esteem and avoids feelings of embarrassment or inadequacy?

- People are less likely to feel embarrassed or inadequate when they have a clearer understanding of the changes they are experiencing.
- People with MS are reassured to know that changes in libido or ability to achieve orgasm, for example, may be caused by neurologic changes or

medication. This helps them externalize the problem—i.e., blame MS rather than themselves—and maintain self-esteem.

- Well partners are reassured to know that the changes in libido or sexual responsiveness are not a reflection of their partner's decreased attraction to them or loss of affection for them.
- Your ability to talk comfortably about sexual issues and listen/respond to your patients' questions and concerns helps protect their self-esteem and reduce their discomfort.

- Talking openly about MS-related sexual changes conveys the clear message that they are neither unique in having these problems nor alone in their efforts to deal with them.
- Some people may appreciate your concern for their sexual well-being, but still prefer to learn the details of MS-related sexual dysfunction from written materials. The local chapter of the National MS Society can provide you with written materials to keep on hand in your office (1-800-344-4867).

### 3. What are the most important points for me to discuss with my patients?

- Recent prevalence studies indicate that approximately 70% of people with MS experience changes in sexual function.
  - The prevalence of sexual dysfunction is higher in MS than in other chronic diseases, and almost five times higher than in the general population.
  - Sexual problems in MS can be divided into *primary*, *secondary*, and *tertiary* types:
    - **Primary sexual dysfunction** occurs as a result of demyelinating lesions in the spinal cord and brain that *directly* impair sexual feelings and/or response. Examples include:
      - Decreased or absent libido
      - Altered genital sensations or paresthesias
      - Decreased or absent genital sensations
      - Decreased frequency or intensity of orgasms
      - Erectile dysfunction
      - Decreased vaginal lubrication or clitoral engorgement
      - Decreased vaginal muscle tone
    - **Secondary sexual dysfunction** refers to changes in sexual function that result *indirectly* from other MS symptoms or medical/pharmacological interventions. The following MS symptoms can interfere with sexual expression:
      - Fatigue interferes with interest, activity level, and spontaneity.
      - Spasticity impacts comfort and positioning.
      - Non-genital sensory paresthesias reduce comfort and pleasure.
      - Weakness interferes with sexual activity.
      - Pain reduces sexual activity and pleasure.
      - Bladder/bowel dysfunction causes anxiety and discomfort.
      - Tremor interferes with sexual activity.
      - Cognitive impairment impacts attention and psychogenic stimulation.
- The following medications can interfere with the sexual response:
- Tricyclic antidepressants and selective serotonin reuptake inhibitors for

- depression can inhibit libido and orgasm.
- Anticholinergic and antimuscarinic medications reduce vaginal lubrication.
- Antispasticity medications produce significant fatigue.
- Anti-seizure medications used to control pain or tremor produce significant fatigue.
- **Tertiary sexual dysfunction** refers to the psychological, social, and cultural issues that interfere with sexual feelings and/or response. Examples include:
  - “Disabled people aren’t sexually attractive.”
  - “I can’t be both a caregiver and a lover.”
  - “If I don’t like myself any more, how can I expect someone else to find me attractive?”
  - “This isn’t the same person I married.”
  - “He/she doesn’t find me attractive now that I’m a burden.”
  - “With everything else that’s going on, sex is the last thing I care about right now.”
- *With the exception of certain types of erectile dysfunction, MS-related sexual changes do not impact fertility. Men and women with MS need to make the same kinds of family planning/contraceptive decisions as any other couple.*

#### 4. Once we have discussed these MS-related sexual problems, how can I engage my patients in the necessary problem-solving behaviors and promote confidence and hope?

- It is important to emphasize that a variety of treatments/management strategies are available to address *primary, secondary, and tertiary* sexual dysfunction.
- A thorough assessment of sexual function typically includes:
  - Multi-disciplinary assessment of primary, secondary, tertiary factors
  - Sexual history, psychosocial and family history, couple’s interview
  - Self-report instruments
  - Review of medical history
  - Evaluation of current medication regimen
  - Specialized medical tests (e.g., penile Doppler sonography, nocturnal penile tumescence, injection of prostaglandin into corpus cavernosum)
- The rehabilitation of sexual function includes:
  - Education and support to promote active problem-solving
  - Medical symptom management, including adjustment of medications
  - Communication skills training—between partners and between patient and medical team
  - Counseling targeting intimacy and sexuality
- Management of **primary sexual dysfunction in men** includes:
  - Oral medications such as sildenafil citrate (Viagra), vardenafil (Levitra), tadalafil (Cialis)
  - Intracavernous injection therapy (alprostadil (Prostin VR), papaverine)
  - Intraurethral suppositories (alprostadil (MUSE))

- Topical medication (Alprostadil (Alprostadil))
- Vacuum erection device
- Penile prostheses
- Body Mapping Assessment/Exercise may enhance arousal by enabling the man with MS to identify parts of his body and types of touch that feel good/stimulating, and then communicate this information to his partner (see chapters on sexuality in the recommended readings).
- Sexual aids such as vibrators or other devices
- Management of **primary sexual dysfunction in women** includes:
  - Medications such as phenytoin (Dilantin), carbamazepine (Tegretol), gabapentin (Neurontin), and duloxetine hydrochloride (Cymbalta) may relieve painful paresthesias.
  - Vibrators and other sexual aids may provide added or more focused stimulation.
  - Water-soluble lubricants (e.g., K-Y Jelly, Astroglide, Replens) enhance comfort.
  - Pelvic floor exercises (e.g., Kegel) may enhance orgasmic response.
  - Body Mapping Assessment/Exercise may enhance arousal by enabling the woman with MS to identify parts of her body and types of touch that feel good/stimulating, and then communicate this information to her partner.
  - Counseling interventions to enhance intimacy and communication
- Management of **secondary sexual dysfunction in men and women** requires careful monitoring of other MS symptoms and their management.
- Coping with bladder dysfunction involves:
  - Tailoring symptomatic treatments (medications and intermittent catheterization) around times of anticipated sexual activities
  - Coping with urinary leakage by avoiding fluid intake for a few hours prior to intercourse; males can use condoms for small amounts of leakage.
- Coping with catheters involves:
  - Men: Folding the indwelling catheter over the penis and placing a condom over the penis and catheter.
  - Women: Taping the drainage tube to the abdomen to prevent excess pulling or pressure.
  - Utilizing varied sexual positions to minimize catheter pulling or pressure.
  - Using a longer drainage tube and placing the bag out of the way.
  - As permitted by the physician—temporarily disconnecting the bag and clamping the catheter.
- Coping with impairments of attention/concentration:
  - Create a romantic/sexually-stimulating environment with minimal distractions.
  - Create rituals for regaining attention when distraction occurs.
  - Learn to alter the pace of sexual touching and communication when distraction occurs.
- Coping with SSRI-related sexual dysfunction:
  - Some patients can tolerate SSRI holidays one day a week, which may reduce the sexual dysfunction for that day.

- Adding a low dose of the antidepressant medication bupropion (Wellbutrin) to the SSRI regimen sometimes helps counteract the sexual side effects.
- Adding a phosphodiesterase-5 inhibitor for men (Viagra, Levitra, Cialis)
- A variety of management strategies are available to address **tertiary sexual dysfunction in men and women**:
  - Counseling/education concerning ways to talk comfortably about sexual feelings, concerns, and behaviors
  - Counseling focusing on attitudes that interfere with sexual enjoyment (e.g., goal-oriented sex in which orgasm is considered the only satisfactory “outcome”; role conflict; intimacy vs. sex; poor self-esteem and/or body image; negative reactions to physical disability)
- Body Mapping Exercise for enhancement of body image
- Couple’s education/counseling to enhance sensual, erotic, and “special person” aspects of the relationship
- Stress-management training to manage anxiety
- Couple’s counseling to enhance adaptation to MS, improve empathy and understanding, and improve communication
- Anger management training
- Reassure your patients that you will help them with this problem and provide any necessary referrals (e.g., to a sex therapist, physician, nurse specialist, or psychologist who is familiar with MS and specializes in the treatment of sexual dysfunction). Your local chapter of the National MS Society (1-800-344-4867) can help you and your patients identify these resources in the community.

### 5. What is the best format for providing this information?

- Different people learn differently—even within a single couple. Face-to-face conversations, printed literature, and audiotapes are all acceptable ways to provide information about sexual dysfunction. Once the topic has been raised by you or your patient, you can offer alternative sources of information.
- Regardless of the format of the information provided, it is important to make yourself available for questions and reiteration of the information.
- The topic of sexuality cannot be addressed comfortably or thoroughly in a regular office visit. Once the subject has been raised, you might want to schedule an additional visit to focus on sexual questions and concerns.

### 6. When and how should I involve a significant other in this discussion?

- With your patient’s consent, it is usually helpful to invite the spouse or partner to join in an early discussion of MS and the types of symptoms it can cause. This type of early education can prepare couples to recognize some of the problems that might arise.
- In the event that the person with MS develops sexual symptoms, it is important to encourage open communication with



the partner so that the appropriate interventions can be initiated. You then have the opportunity to help the couple clarify the problem, avoid unnecessary

misunderstanding or blame, and set the stage for treatment interventions and effective problem-solving strategies.

## 7. What kinds of emotional responses can I expect from my patients and their significant others?

- Your ability to talk comfortably about sexual issues will reduce the embarrassment and awkwardness that so often surrounds this topic.
- Most people with MS will be relieved to know that there is a neurologic basis for the changes they are experiencing, and treatment strategies to address the problems.
- Spouses/partners are often relieved to know that the “fault” does not lie with them.
- While some patients will be reluctant to discuss sexual problems with you or another professional, a surprising number are eager for information, support, and intervention.

## 8. What resources are available to support my patient?

- Chapters of the National MS Society (1-800-344-4867) offer:
  - *Relationship Matters* program—a series of interactive classes for couples living with MS
  - Educational programs and support groups
  - Referrals to professionals in the community who specialize in the treatment of sexual dysfunction and are familiar with MS
  - Printed materials about sexuality and a range of other topics available free of charge (also available from the National MS Society website: [www.nationalMSsociety.org/Brochures](http://www.nationalMSsociety.org/Brochures))
    - *MS and Intimacy*
    - *Fatigue: What You Should Know*
    - *Taming Stress in Multiple Sclerosis*
    - *Multiple Sclerosis and Your Emotions*
    - *Urinary Dysfunction and Multiple Sclerosis*
- *MS and the Mind*
- *Sobre los Problemas Sexuales Que No Mencionan los Médicos*
- The National MS Society website ([www.nationalMSsociety.org](http://www.nationalMSsociety.org)) offers information and interactive programming on a wide variety of topics (e.g., disease-modifying therapies, symptom management, research), as well as access to local resources and events.
  - Information on Sexuality and Intimacy (<http://www.nationalMSsociety.org/Intimacy>)
- **Additional recommended websites:**
  - Multiple Sclerosis Society of Canada [www.mssociety.ca](http://www.mssociety.ca)
  - International Federation of Multiple Sclerosis Societies/  
The World of Multiple Sclerosis <http://www.msif.org/>
  - Pharmaceutical Company Support Programs



- Betaseron  
BETAPLUS  
[www.betaseron.com](http://www.betaseron.com)
  - Avonex  
MS Active Source  
[www.msactivesource.com](http://www.msactivesource.com)
  - Copaxone  
Shared Solutions  
[www.sharedsolutions.com](http://www.sharedsolutions.com)
  - Novantrone  
[www.novantrone.com](http://www.novantrone.com)
  - Rebif  
MS Lifelines  
[www.ms lifelines.com](http://www.ms lifelines.com)
  - Tysabri  
TOUCH Prescribing Program  
[www.tysabri.com](http://www.tysabri.com)
- **Recommended reading:**
    - Kalb R (ed.). *Multiple Sclerosis: A Guide for Families* (3rd ed.). New York: Demos Medical Publishing, 2006.
    - Kalb R (ed.). *Multiple Sclerosis: The Questions You Have; The Answers You Need* (4th ed). New York: Demos Medical Publishing, 2008.
    - Kalb R, Holland N, Giesser B. *Multiple Sclerosis for Dummies*. Hoboken, NJ: Wiley Publishing, 2007.
    - Kroll R, Klein E. *Enabling Romance: A Guide to Love, Sex, and Relationships for the Disabled*. New York: Harmony Books, 1992.

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Dr. Foley is the Director of Neuropsychology and Psychosocial Research at the Bernard Gimbel Comprehensive MS Center at Holy Name Hospital in Teaneck, NJ. Dr. Foley has dedicated his career to improving psychosocial rehabilitation and treatment methods in MS. His research projects have focused broadly on developing outcome measures and/or psychosocial treatments for depression, cognitive function, and sexual function in MS. The federal government and private foundations in the United States and England have funded his research.

Dr. Foley has served as President of the Consortium of Multiple Sclerosis Centers, an international organization of MS professionals. He has numerous publications and book chapters on sexual dysfunction and other aspects of MS, and has received recognition from the Academy of Psychosocial Medicine for his research.

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According to the Cleveland Clinic, issues of sexual dysfunction are universally common. In fact, 43% of women and 31% of men report some level of difficulty in the bedroom, whether the concern is physiological or psychological. [It] means you concentrate much more on the emotional, intimate connection you have with the person you're talking to instead of just the facts. Dr. Torrisi is an AASECT certified sex therapist with a PhD in human sexuality and also the founder and supervising therapist at the Long Island Institute of Sex Therapy. Sexual dysfunctions that occur in the desire and arousal phases of the sex response cycle (see Chapter 3) seem more common than others in the context of chronic medical disorders. The orgasm phase appears less vulnerable to disruption by illness (apart from He was interviewed by a resident who could talk easily with patients about sexual problems because of a recent and special educational experience in a clinic that focused on patients with sexual disorders. The patient identified problems in a relationship with a woman as an important reason for his present mood state. The real world exposed the Sex and the City Mythology as total bullshit in every way, but it took me at least a year of emotionally pulverizing experiences before the reality finally trumped the mythology. Three attempts at flings ended up thusly: A girl who had been a fairly cute 7 as a twenty year old was now a titless, sickly-looking 5 in her thirties. But I was lonely and she did a good job of fronting like the carefree sexual gal by binge drinking and talking about sex all the time. But oddly, every date ended with her jabbering away narcissistically and postponing actual sex. After her e