

Talking About Sexual Dysfunction

Talking with your MS patients about difficult topics



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The National MS Society's Professional Resource Center (PRC) is a resource for clinicians, offering professional publications, clinical consultations, and literature search services, as well as information on health insurance issues, long-term care options, and the development of MS specialty clinics. Physicians are invited to consult via email with MS specialist colleagues at MD_info@nmss.org. Allied health professionals are invited to consult via email with MS specialist colleagues at healthprof_info@nmss.org.

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Talking about Sexual Dysfunction

By Frederick Foley, PhD

An Endorsement from Cathy-Lee Benbow, MSW, RSW

“Multiple Sclerosis can challenge many areas of a person’s life. This publication addresses issues which are often present for people living with MS, but which both patients and health care professionals struggle to address. Health care professionals and ultimately patients will benefit from this excellent resource produced by the MS Society of Canada.”

About the Endorser

Cathy-Lee Benbow received a Bachelor of Social Work from King’s University College, University of Western Ontario in 1984. She achieved certification through the Ontario College of Certified Social Workers in 1986 and remains a registered social worker in the Ontario College of Social Workers and Social Service Workers. She received a Master of Social Work from the University of Toronto in 1988. Cathy-Lee has practiced clinical social work and held administrative positions in a number of health care settings within hospitals and the community. She has been a field instructor within both the undergraduate and graduate programs for the Faculty of Social Work at King’s University College, University of Western Ontario, London, Ontario and Sir Wilfred Laurier University, Waterloo, Ontario.

Cathy-Lee Benbow is currently the Coordinator of the Multiple Sclerosis Clinic at the London Health Sciences Centre, London, Ontario, where she carries both clinical and administrative responsibilities. She has presented at numerous professional health care conferences and patient workshops on a variety of topics ranging from the psychosocial impact of MS to sexuality and MS.

About the Author

Frederick Foley, PhD

Frederick Foley received his PhD in Clinical Psychology from Fordham University in 1986. Since then, he has been on the faculty at Albert Einstein College of Medicine and Ferkauf Graduate School of Psychology, both of Yeshiva University, in Bronx, NY. He is currently an associate professor of psychology.

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 is on the board of directors of the Consortium of Multiple Sclerosis Centers, an international organization of MS professionals, and serves as Past-President for this organization. He has numerous publications and book chapters on his work in MS, and he has received recognition from the Academy of Psychosomatic Medicine for his research.

Talking about Sexual Dysfunction

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 dysfunction 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 gynaecological 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 health care 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 MS Society of Canada can provide you with written materials to keep on hand in your office.

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

- Prevalence studies indicate that 44–80% of people with MS experience significant sexual problems.

- The prevalence of sexual dysfunction is higher in MS than in other chronic diseases, and almost five times higher than in the healthy 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. MS symptoms that can interfere with sexual expression include:

- 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

Medications that can interfere with the sexual response include:

- 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 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 behaviours 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 in 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
 - Counselling targeting intimacy and sexuality
 - Management of **primary sexual dysfunction** in males 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

- 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 and carbamazepine may relieve painful paresthesias
 - Vibrators and other sexual aids may provide added or more focused stimulation
 - Water-soluble lubricants (e.g., K-Y Jelly[®],) 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
 - Counselling 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: Fold the indwelling catheter over the penis and placing a condom over the penis and catheter
 - ▶ Women: Tape the drainage tube to the abdomen to prevent excess pulling or pressure
 - ▶ Utilize varied sexual positions to minimize catheter pulling or pressure
 - ▶ Use a longer drainage tube and placing the bag out of the way
 - ▶ As permitted by the physician – temporarily disconnect the bag and clamp the catheter
 - Coping with impairments of attention/concentration:
 - ▶ Create a stimulus-saturated, minimally distracting environment for sexual activity

- ▶ 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 another anti-depressant medication in low dose (Welbutrin®) to the SSRI regimen sometimes help 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:**
 - Counselling/education concerning ways to talk comfortably about sexual feelings, concerns, and behaviours
 - Counselling 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/counselling to enhance sensual, erotic, and “special person” aspects of the relationship
 - Stress-management training to manage anxiety
 - Couple’s counselling 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).

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 visual or audio materials 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?

The Multiple Sclerosis Society of Canada

- The Multiple Sclerosis Society of Canada offers educational programs, support groups, and other resources for:
 - Individuals living with a diagnosis of MS
 - Individuals awaiting a diagnosis with respect to MS
 - Individuals close to a person with MS, such as their family and friends
 - Caregivers of a person with MS

In addition to serving its primary clients, Society volunteers and staff also provide information and support to health professionals, employers, institutions and students.

Based upon needs and available resources, the MS Society of Canada's units, chapters, divisions, and national office provide Client Services that encompass:

- Information and referral
- Education
- Support
- Advocacy
- Funding
- The MS Society of Canada has educational materials on a wide range of topics. Your patients can obtain these and other materials free of charge from their local division or chapter (1-800-268-7582) or visit the website at www.mssociety.ca:
 - Sexuality and MS
 - Taming Stress in Multiple Sclerosis
 - Multiple Sclerosis and Your Emotions
 - Living Well with MS: Mind Matters
 - Understanding Bladder Dysfunction
- The Multiple Sclerosis Society of Canada website (www.mssociety.ca) offers information on a variety of topics related to MS as well as information regarding local services, programs, fundraising events and much more.

MS Clinics

- The Multiple Sclerosis Society of Canada is proud to work with a network of specialized MS clinics across the country. Clinic services vary, but most offer a wide range of services, delivered by a multi-disciplinary health care team. Visit our website (www.mssociety.ca) for a list of MS clinics across Canada.

Additional Recommended Websites:

- The National Multiple Sclerosis Society (U.S.A.) website (www.nationalmssociety.org) offers information and interactive programming on a wide variety of topics (e.g., disease-modifying therapies, symptom management, research):
 - Web Spotlight on MS and Intimacy
www.nationalmssociety.org/spotlight-intimacy.asp
- The Multiple Sclerosis International Federation/The World of Multiple Sclerosis www.msif.org
 - MS in Focus: Intimacy and Sexuality
www.msif.org/en/publications/ms_in_focus/index.html
- CenterWatch Clinical Trials Listing Service™
www.centerwatch.com
- Consortium of Multiple Sclerosis Centers
www.ms-care.org
- National Institutes of Health (NIH) Clinical Trials Listing Service
www.clinicaltrials.gov

Pharmaceutical Company Support Programs:

Betaseron (Berlex)

MSPathways

1-800-977-2770

www.mspathways.ca

Avonex (Biogen)

MS Alliance

1-888-456-2263

www.msalliance.com

Copaxone (Teva Neuroscience)

Shared Solutions

1-800-283-0034

www.ms-watch.ca

Rebif (Serono Canada)

Multiple Support Program

1-888-677-3243

www.serono-canada.com

Recommended Reading:

- Kalb R (ed.). **Multiple Sclerosis: A Guide for Families** (3rd ed.). New York: Demos Medical Publishing, 2005.
 - Ch. 4 Foley F. **Sexuality and intimacy in multiple sclerosis.**
- Kalb R (ed.). **Multiple Sclerosis: The Questions You Have; The Answers You Need** (3rd ed.). New York: Demos Medical Publishing, 2004.
 - Ch. 12 Foley, F, Werner, M. **Sexuality.**
- Kaufman M, et al. **The Ultimate Guide to Sex and Disability: For all of us who live with disabilities, chronic pain, & Illness.** San Francisco: Cleis Press Inc, 2003.
- 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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How to Reach the MS Society

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OUR MISSION

To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life

Contact the Multiple Sclerosis Society of Canada

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