

Talking with your MS patients about difficult topics



Talking About Elimination Problems

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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 Elimination Problems

By Nancy Holland, RN, EdD

An Endorsement from Colleen Harris, RN, MN

“Multiple Sclerosis is a complex illness with diverse possible symptoms. This publication will not only assist health professionals in finding the right words in tackling a topic like elimination problems, but will also provide health professionals with a wealth of resources for helping their patient to manage this symptom. Both health professionals and ultimately patients will benefit from this excellent resource produced by the Multiple Sclerosis Society of Canada.”

About the Endorser

Colleen Harris is the Nurse Coordinator/Nurse Practitioner of the University of Calgary MS Clinic, where she has been involved in multi-disciplinary care for the past twenty years. She completed a diploma-nursing program at Foothills Hospital and later obtained both a Bachelor's and Master's Degree in nursing, as well as a post Masters Nurse Practitioner Certificate through the University of Calgary. She holds an Adjunct Assistant Professor appointment with the faculty of Nursing at the University of Calgary. Her interests specific to MS include intrathecal baclofen therapy, health outcomes research, and nursing education. Colleen, along with several of her MS nursing colleagues from North America, Europe and Australia, was involved in the creation of the International Organization of MS Nurses (IOMSN). She is a past president of IOMSN, which has a membership of over 1000 and is rapidly growing.

About the Author

Nancy Holland, RN, EdD

Nancy Holland, RN, EdD is vice president of Clinical Programs at the National Multiple Sclerosis Society in New York, with a primary focus on professional education. She earned a doctorate in higher and adult education from Teachers College, Columbia University, and holds undergraduate and graduate degrees in nursing.

Dr. Holland received a Career Development Award from the National Institute on Disability and Rehabilitation Research and is author/editor of more than 60 MS-related articles, books and chapters including *Multiple Sclerosis: A Guide for Patients and Their Families*, *Multiple Sclerosis: A Guide for the Newly Diagnosed*, *Comprehensive Nursing Care in Multiple Sclerosis*, *Multiple Sclerosis: A Self-Care Guide to Wellness*, and *Multiple Sclerosis in Clinical Practice*. She is a founding member of the Board of Directors of the International Organization of MS Nurses (IOMSN), and served as the first chair of the IOMSN Research Committee.

Talking about Elimination Problems

Introduction

This booklet is designed to facilitate conversations with your multiple sclerosis patients about elimination problems. Like the other topics in this series, elimination is one that patients are often uncomfortable raising with their doctors and other health care professionals. The following information will help you communicate with your patients about this difficult topic, in terms that are easily understood by the layperson.

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

- Patients should be asked about bladder and bowel function during each office visit. By raising the subject yourself, you are alerting them to the fact that MS can interfere with elimination and relieving them of the burden of having to bring up this sensitive subject.
- Ask questions about specific symptoms (e.g., constipation, urinary urgency, urinary frequency, difficulty voiding). People are often surprised to learn that MS can cause these types of problems and may even have experienced some of these changes before their MS diagnosis was confirmed.
- If your patient reports no current problems but asks what types of problems might occur, you can describe some of the more common symptoms and refer the person to their MS Society of Canada division (1-800-268-7582) or the publications section of the website: www.mssociety.ca for information about bladder and bowel function.
- More detailed information about symptoms and treatments should be given if and when those symptoms arise.

2. How can I address this topic in a way that will reduce anxiety and avoid embarrassment and loss of self-esteem?

- As with all sensitive topics, your best strategy is to address bladder and bowel functions in a routine, matter-of-fact manner. This will increase the

likelihood that your patients will talk about problems they are having, and also give them the vocabulary with which to do so. Your patients' comfort in talking about changes in bowel and bladder function will directly reflect your comfort in raising these issues with them.

- It is important to let your patients know that changes in bowel and bladder function are common in MS. Knowing that their problems are not unique, and that you have dealt with these issues many times, will help your patients feel less self-conscious and embarrassed.
- Providing your patients with print materials about bladder and bowel function, or referring them to the MS Society of Canada for these materials, will reinforce your message that these types of problems are common in MS. It will also allow them to familiarize themselves with the information in the privacy of their own home.
- Encourage your patients to talk with other people who have MS. Support groups and chat rooms can provide people with a comfortable venue for discussing difficult or embarrassing topics. Many people find it helpful and reassuring to be able to talk, share strategies, and laugh about problems that they would never have thought they could discuss with others.

3. What is the most important information for me to convey to my patients about MS-related elimination problems?

- As many as 80–90% of people will experience transient or persistent urinary symptoms. Bowel problems occur somewhat less frequently.
- These symptoms can be successfully managed, particularly if they are addressed early on, before the problems have become severe.
- Left unmanaged, these symptoms can interfere with daily activities, lead to feelings of anxiety and loss of self-esteem, and cause significant health problems.
- Successful management of these symptoms is an ongoing process, requiring effective doctor-patient communication and teamwork.
- Referral to a specialist (e.g., urologist, gastroenterologist) or a visiting nurse service may be required.

4. What is the most important information for me to give my patients about bladder symptoms in MS?

- Urinary tract infections are common in MS, usually resulting from incomplete emptying of the bladder, sometimes accompanied by buildup of mineral deposits.
 - Patients should report symptoms of urinary urgency, frequency, burning sensation while voiding, foul smelling or dark-colored urine, abdominal or low back pain, elevated body temperature, or increased spasticity.
 - The risk of infection can be reduced by taking the following steps to increase the acidity of the urine: 1) drinking cranberry juice or taking cranberry tablets; 2) limiting intake of citrus juices; and 3) drinking adequate amounts of water.
- People with urinary symptoms tend to decrease their fluid intake in order to avoid accidents. In addition to increasing the risk of urinary tract infections, this reduction in fluids worsens urinary symptoms; the concentrated urine irritates the bladder wall, resulting in increased bladder hyperactivity (e.g., symptoms of urgency and frequency).
- Bladder dysfunction in MS typically falls into one of two categories:
 - **Failure to Store** – As a result of nerve damage in the central nervous system, small amounts of urine in the bladder cause uninhibited bladder contractions. These contractions are experienced as a strong urge to urinate. The person may feel the need to urinate frequently and urgently even though there is very little urine in the bladder.
 - **Failure to Empty** – As a result of nerve damage in the central nervous system, the person may be unaware of the need to urinate. Although the bladder fills with urine, the spinal cord is unable to signal the brain of the need to void, or the bladder sphincter muscle of the need to relax and release the urine. The urine remains in the bladder, which continues to fill and expand.

Note: At times, uninhibited contractions of the bladder work to expel urine at the same time that the sphincter muscle contracts to trap urine in the bladder. The person experiences the urge to urinate, but may have difficulty initiating the flow.

Because both types of dysfunction can cause similar symptoms (urinary urgency, frequency, hesitancy, nocturia, incontinence), testing is needed to determine the nature of the problem and identify appropriate treatment. The first step is to test for a urinary tract infection. If no infection is found, measurement of the post-void residual (PVR), the amount of urine remaining in the bladder after urination, should be performed. PVR can be measured either by straight catheterization or by ultrasound.

- **Failure to Store** is managed with:
 - Medication to relax the overactive bladder (e.g., anticholinergic agents such as Tofranil[®], Ditropan XL[®], and Pro-Banthine[®], or the antimuscarinic agent, Detrol[®]). **Patients need to be told that these medications can cause dry mouth and increase constipation.**
 - Behavioural strategies (eight glasses of fluid per day; reduced intake of caffeine, aspartame and alcohol that irritate the bladder; reduced fluid intake after 6 p.m. or two hours before any activity where no bathroom is available; use of an absorbent pad for added security).
 - DDAVP[®] can be used at night to help with nocturia (with periodic monitoring of electrolytes).
- **Failure to Empty** is managed with intermittent self-catheterization (ISC):
 - Although the idea of ISC is frightening and distasteful for most people, it is a relatively simple, pain-free way to eliminate residual urine.
 - ISC can actually improve bladder function by acting as a kind of physical therapy for the bladder.
 - ISC can make it possible for a person to resume activities outside the house without having to worry constantly about bladder accidents.
 - ISC prior to sexual activity can reduce anxiety about potential incontinence.
 - Talking to other people who catheterize (e.g., in a support group) can reduce the person's anxiety.
- If ISC does not eliminate symptoms, antimuscarinic or anticholinergic medications can be added. An antispasticity agent such as Lioresal[®] may also be used.
- For those people for whom ISC and anticholinergic or antimuscarinic medications are insufficient to manage the problem, the doctor may recommend the use of an indwelling catheter.

5. Should I raise the question of sexual problems with someone who is experiencing bladder dysfunction since they often occur together?

- As with bladder and bowel function, questions about sexual function should be routinely and matter-of-factly raised during regular visits (see Talking about Sexual Dysfunction).
- If a patient is experiencing significant bladder symptoms, but seems uncomfortable talking about sexual function, it may be helpful to say that you are raising the question because these types of problems often occur together. A person who is experiencing sexual difficulties, but feels ashamed or embarrassed to discuss them with you, may find it easier knowing that these problems are related to MS.

6. What is the most important information for me to give my patients about bowel symptoms?

- Adherence to management strategies is important for achieving and maintaining healthy bowel functioning.
- Bowel symptoms in MS include constipation, bowel urgency, and bowel incontinence. Loose stool that isn't caused by some type of infection or medication is usually the result of impaction or stool blockage, whereby looser stool from higher in the digestive tract leaks out around the impaction.
- Constipation, the most common bowel symptom, is defined as infrequent, incomplete, or difficult bowel movements.
 - Patients should be encouraged to report any significant change in their regular bowel habits.
 - A person should not go more than three to four days without a bowel movement unless that has been their normal pattern.
- Constipation can be caused by a variety of factors:
 - Neurologic changes
 - Lack of sensation in the rectal area
 - Weakened abdominal muscles
 - Lack of mobility and exercise
 - Insufficient fluid intake
 - Medications, particularly those used to treat urinary symptoms

- Inadequate bowel routines, particularly the lack of a regular and relaxed time for elimination.
- Constipation is best handled by a routine involving:
 - A regular and relaxed time for elimination
 - Appropriate diet with adequate fibre to increase the moisture-retaining bulk of the stool (e.g., bran, grains, fresh fruits and vegetables, prunes)
 - Adequate fluid intake – at least eight glasses of water per day
 - Adequate exercise
 - Dietary measures can be augmented with **natural** bulk supplements like Metamucil® and a stool softener such as Colace®
 - If necessary, Milk of Magnesia® or a glycerin suppository may be used
 - Enemas, such as Fleet® can be used if the other measures are insufficient
 - **Patients should be reminded that regular use of enemas is to be avoided since they can lead to dependency and increase constipation.**
- Constipation can cause other symptoms to flare:
 - Spasticity
 - Urinary symptoms
- Bowel incontinence, usually caused by spasms of the involuntary muscles of the bowel or loss of tone and/or sensation in the rectal area, is best managed with dietary measures and a consistent bowel regimen. Anticholinergic medications may be helpful, but require careful monitoring of bladder function.

7. What is the best format for providing this information?

- Open discussion with the patient so that he or she feels comfortable describing symptoms and asking questions.
- Printed materials that the patients can take home and read.
- Encouragement to call with any questions or concerns.

8. What is the best way to talk to those spouses/partners who need to be involved in catheterization procedures?

- Explain the importance of catheterization for maximizing bladder function and overall health, and avoiding unnecessary complications.
- Explain how other symptoms (e.g., weakness, spasticity, sensory changes, incoordination) can interfere with ISC.

- Describe the steps involved in ISC.
- Recognize and support the spouse/partner's emotional reactions to this change in the relationship.
- Recommend a support group or other counselling if necessary.

9. What kinds of emotional responses can I anticipate from my patients and spouses/partners?

- Some patients are so embarrassed about bladder and/or bowel symptoms that they will not talk about them with you, even when asked.
- Most people are relieved to know that their constipation is related to MS and can be managed with appropriate strategies.
- Some patients are so resistant to ISC that they will withhold information about symptoms they are having in order not to be told to catheterize.
- Some patients are so relieved to know that there are bladder medications and strategies that will give them back their comfort and freedom that they comply without difficulty. (If any of these patients who are successful and comfortable with ISC are willing to share their experiences with others, they can be very helpful to people who are frightened or resistant.)
- Some spouses/partners are willing and able to provide the necessary assistance with catheterization; others are not. If, in spite of information about the importance of catheterization and emotional support in the form of counselling, the spouse/partner is non-compliant, arrangements must be made for someone else to provide the help, or an indwelling catheter must be used. (See Sexual Dysfunction booklet for ways to address the impact of caregiving activities on the sexual relationship.)

10. What should I say/do if the patient's emotional responses are interfering with treatment compliance?

- Emphasize the importance of effective symptom management in order to address the problems, avoid complications, and maintain health.
- Reinforce the idea that utilizing effective management strategies is a way to take charge of one's MS and regain a sense of control and independence.
- Encourage participation in a support group.
- Recommend individual counselling with a therapist who is familiar with MS.

11. When and how do I introduce the possible need for surgical intervention?

- Most urinary symptoms respond to the kinds of treatments described above. Surgical intervention might be required if:
 - Adequate bladder control is not achieved with some combination of ISC, anticholinergic or antimuscarinic medications, and antispasticity agents.
 - The person is unable to tolerate an indwelling catheter.
- The subject of surgical intervention should be raised once all other measures have been tried. It should be made clear, however, that the surgical procedures do not “cure” the bladder dysfunction.
- Emphasis should be placed on the need for surgery to manage uncontrolled bladder symptoms, prevent infection, and promote health.
- Patients in need of surgical interventions may need supportive counselling to deal with feelings of grief, failure, and/or loss of self-esteem.

12. What types of resources are available to support/educate my patients?

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:
 - Understanding Bladder Dysfunction
 - Understanding Bowel Problems
- 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
 - Web Spotlight on MS and Personal Care
www.nationalmssociety.org/BladderBowel
- The Multiple Sclerosis International Federation/The World of Multiple Sclerosis www.msif.org
 - In Focus: Special Focus on dealing with Bladder Problems
www.msif.org/en/publications/ms_in_focus/index.html
- CenterWatch Clinical Trials Listing Service™ www.centerwatch.com
- Consortium of MS 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

Copaxone (Teva Neuroscience)

Shared Solutions

1-800-283-0034

www.mswatch.ca

Avonex (Biogen)

MS Alliance

1-888-456-2263

www.msalliance.com

Rebif (Serono Canada)

Multiple Support Program

1-888-677-3243

www.serono-canada.com

Recommended Reading:

- Holland NJ, Halper J (eds.). **Multiple Sclerosis: A Self-Care Guide to Wellness** (2nd ed.). New York: Demos Medical Publishing, 2005.
 - Ch. 7: Holland NJ, O’Leary M. **Bladder and Bowel Management.**
- Kalb R (ed.). **Multiple Sclerosis: The Questions You Have; The Answers You Need** (3rd ed.). New York: Demos Medical Publishing, 2004.
 - Ch. 4: Halper J. **Nursing Care to Enhance Wellness.**
- O’Connor PD. **Multiple Sclerosis: The Facts you Need.** Toronto: Key Porter Books, 2002.

Other Booklets in this Series:

Talking about the Diagnosis of Multiple Sclerosis

Barbara Giesser, MD

Talking about Progressive Disease

Aaron Miller, MD

Talking about Depression and Other Emotional Changes

Sarah Minden, MD

Talking about Sexual Dysfunction

Frederick Foley, PhD

Talking about Cognitive Dysfunction

Nicholas LaRocca, PhD

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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