

TALKING WITH YOUR PATIENTS ABOUT **ELIMINATION PROBLEMS IN MS**

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**National
Multiple Sclerosis
Society**

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Introduction

Use this resource to help 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 healthcare professionals. Yet, untreated bladder problems can lead to significant morbidity and mortality. The following information will help you communicate with your patients about this difficult topic, in terms that are easily understood by the layperson.

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

- Ask your patients 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 specific questions about bladder symptoms (urgency, frequency, hesitancy, incontinence, leakage, nocturia, odor, history of UTIs) and bowel symptoms (constipation, bowel movement frequency, incontinence, fecal leakage, involuntary bowel, excessive bloating or gas). 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 the National MS Society (1-800-344-4867) or the Society's website (national.mssociety.org/BladderBowel) for information about bladder and bowel function.
- Provide more detailed information about symptoms and treatments if and when those symptoms arise but by asking patients about their bladder and bowel habits at each visit, patients will become more comfortable discussing these sensitive issues and more likely to address symptoms earlier.

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 function 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.
- 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 or web links about bladder and bowel function or referring them to the National MS Society for these materials, will reinforce

your message that these types of problems are common in MS and that there are many treatment options available to address these issues. 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.

What is the most important information to give my patients about MS-related elimination problems?

- As many as 80–90% of people will experience transient or persistent urinary symptoms, with 15% of people experiencing urinary problems as their first symptom. Bowel problems occur in about 50% of patients with MS.
- These bladder and bowel 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 communication and collaborative decision making between the provider and person with MS.
- Referral to a specialist (e.g. urologist, gastroenterologist), pelvic floor physical therapist, or a visiting nurse service may be required.

What is pelvic floor physical therapy and when is a referral appropriate?

- Pelvic floor physical therapy focuses on empowering people to participate active in the management of their symptoms. The pelvic floor specialists educate people to identify symptom early on so that they can report them to their physician or nurse, and offers healthy strategies and behaviors to prevent or delay symptom development. This process includes:
 - Education on proper dietary and lifestyle strategies
 - Proper toileting habits, biomechanics and patterns
 - Customized pelvic floor muscle home exercise program
 - Whole body exercise program
- For those already experiencing bladder, bowel and sexual symptoms, a referral for active and ongoing pelvic floor physical therapy may be indicated. This would include the interventions mentioned above as well as any of the following:
 - Bladder/bowel urgency delay techniques
 - Visceral massage
 - Acupuncture and/or tibial nerve stimulation

- Vaginal and/or rectal internal manual therapy for myofascial trigger point release, scar tissue release, ligament cross frictions, etc.
- Pelvic floor muscle exercise and/or relaxation programs
- Modalities such as computerized EMG biofeedback and/or neuromuscular electrical stimulation
- Education about or fitting for pessary or other orthotic supports
- Because pelvic floor physical therapy is often helpful before bladder, bowel and sexual dysfunction symptoms present, an early referral may be considered.

What can be done proactively to help prevent bladder and bowel symptoms from arising?

- Healthy bladder and bowel dietary and lifestyle choices can help prevent or delay bladder and bowel symptoms from developing.
- Proper toileting postures and habits can help to prevent or delay the development of bladder and bowel symptoms.
- Since a healthy pelvic floor muscle is responsible for closing the bladder and bowel to prevent symptoms of incontinence and must relax fully for complete bladder and bowel emptying, ensuring the good health of this muscle is critical. Just like other muscles, the pelvic floor muscle needs exercise.
- Keeping the pelvic floor muscle strong and healthy will also help to support the bladder and bowel from below. This may prevent, or delay prolapse of the pelvic organs as well as further compromise of bladder and bowel function.
- A qualified pelvic floor physical therapist can educate patients in proper toileting habits and postures to avoid injury to the pelvic floor muscle. Following a pelvic floor muscle assessment, the physical therapies will prescribe a customized exercise program for the prevention or correction of bladder and bowel symptoms.

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

- Early identification of bladder dysfunction is important for overall health and the prevention of serious complications – including death.
- Open communication with the healthcare provider about bladder symptoms and the effectiveness of any interventions is of utmost importance
- 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, pain or 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 may be reduced by taking the following steps: 1) taking cranberry tablets; 2) limiting intake of citrus fruits and juices; 3) drinking adequate amounts of water; 4) ensuring proper toileting postures and patterns; and 5) fully relaxing the pelvic floor muscle to improve bladder emptying during voiding.
- People with urinary symptoms tend to decrease their fluid intake in order to avoid

accidents. In addition to increasing the risk of urinary tract infection, 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). Limiting their fluid intake will also allow the bladder size to decrease, thereby increasing the need to empty more frequently.

- Bladder dysfunction in MS typically falls into one of two categories:
 - **Problems with Storage**—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. The bladder may also ‘fail to store’ if the pelvic floor muscle does not have the necessary strength, endurance or responsiveness to close off the bladder until you reach the toilet.
 - **Problems with Emptying**—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 pelvic floor muscle of the need to relax and release the urine. The urine remains in the bladder, which continues to fill and expand.

At times, uninhibited contractions of the bladder work to expel urine at the same time that the pelvic floor muscle contracts to trap urine in the bladder. The person experiences the urge to urinate but may have difficulty initiating the flow or reduce their normal flow rate.

People who experience emptying problems are more prone to develop urinary tract infections.

A full bladder may also cause other MS symptoms to be more pronounced such as lower extremity spasticity.

Because both types of dysfunction can cause similar symptoms (urinary urgency, frequency, hesitancy, nocturia, incontinence), testing is necessary 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.

A referral to a urologist, who is knowledgeable and experienced in MS bladder issues, can be very helpful. Additional testing, called urodynamics, can be done by a specialist to better assess bladder problems and determine an appropriate treatment plan.

- **Storage problems** are managed with:
 - Conservative, non-pharmacologic interventions, including proper pelvic floor muscle exercises to effectively close the bladder and eliminate leakage.

- Behavioral strategies
 - Sufficient oral fluid intake per day;
 - Reduced intake of caffeine, artificial sweeteners such as aspartame and alcohol and other beverages that irritate the bladder
 - Healthy lifestyle choices such as avoiding smoking and routinely participating in physical activity
 - Reduced fluid intake after 6 p.m. or two hours before any activity where no bathroom is available
 - Use of an absorbent incontinence pad for added security
- Medication to relax the overactive bladder
 - Anticholinergic agents such as imipramine, oxybutynin extended relief, and propantheline, or the antimuscarinic agents, tolterodine, solifenacin succinate, or trospium chloride. Patients need to be told that these medications can cause dry mouth and increase constipation and may impact cognition.
 - Mirabegron, another medication for OAB, works by a different mechanism to relax the bladder muscle and thereby reduce bladder spasticity. This medication does not impact cognition.
 - Percutaneous tibial nerve stimulation (PTNS) is also used to treat a spastic or overactive bladder. A very small needle electrode, inserted in the ankle, transmits a signal to the sacral plexus. Treatments for 30 minutes per week for 12 weeks has been shown to reduce urinary frequency, urgency, nighttime urination and incontinence.
 - For those individuals who do not get sufficient relief from other interventions, botulinum toxin A injected into the detrusor muscle is FDA-approved to treat overactive bladder and urinary incontinence caused by a neurologic condition. This treatment is highly effective, although most people will need to use intermittent self-catheterization following treatment.
 - InterStim® is a small device surgically implanted under the skin that stimulates the sacral nerves and is used to treat overactive bladder, urinary retention and some types of bowel dysfunction.
- **Emptying problems** should be managed as conservatively as possible, with more invasive techniques added as needed.
 - Pelvic floor physical therapy may be helpful to relax the pelvic floor muscle and facilitate bladder emptying.
 - Intermittent self-catheterization can be very effective for certain types of bladder problems, particularly difficulties with bladder emptying.
 - Although the idea of ISC is difficult to accept for many people, it is a relatively simple, pain-free way to eliminate residual urine – and thus avoid problems such as urine leakage and urinary tract infections.
 - 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 or with a peer counselor) can reduce the person's anxiety.
- If ISC does not eliminate symptoms, medications may be added to the management plan. A muscle relaxing agent such as baclofen may be also be used.
- Although not common, sometimes other strategies including an indwelling urinary catheter, or a suprapubic catheter may be needed if other more conservative strategies are not effective.

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 Sexual Dysfunction booklet).
- The pelvic floor muscle anatomically connects the bladder, the uterus (in women) and the bowel and plays a functional role in each pelvic organ. When people experience dysfunction in any pelvic organ, the pelvic floor muscle is at risk of becoming injured. Also, when the pelvic floor muscle is unhealthy, all pelvic organs are at risk of issues. It is important to ask questions about bladder, bowel and sexual function to ensure this cycle is broken and all symptoms are identified so that they may be addressed and treated.
- 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.

What is the most important information to give my patients about bowel symptoms?

- The most important aspect of managing bowel symptoms is the early identification and thorough assessment of the symptoms (constipation, urgency, incontinence).
- Open communication with the healthcare provider about the symptoms, and results of interventions are important to successful management
- As with bladder symptoms, management of bowel symptoms should begin with the most conservative approaches and add more aggressive medical treatment as needed. For example, diet and lifestyle adjustments, behavioral modification and exercise should always be the first line of defense. This may include pelvic floor physical therapy if education in toileting postures and biomechanics and a prescription for a home exercise program is needed.
- Adherence to management strategies is important for achieving and maintaining healthy bowel functioning. Bowel health relies heavily on consistency, so it is important to make

sure that patients are committed to regimented bowel habits.

- Constipation, the most common bowel symptom, is defined as infrequent, incomplete, or difficult bowel movements.
 - Constipation can be caused by a variety of factors:
 - Neurologic changes
 - Lack of sensation in the rectal area
 - Weakened pelvic floor and abdominal muscles
 - Lack of mobility and exercise
 - Insufficient fluid intake
 - Some medications
 - Inadequate bowel routines, particularly the lack of a regular and relaxed time for elimination
 - 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 is best handled by a routine involving:
 - A regular and relaxed time for elimination
 - Appropriate diet with adequate fiber to increase the moisture-retaining bulk of the stool (e.g. bran, grains, fresh fruits and vegetables, prunes)
 - Adequate fluid intake—about 1.5 – 2 L per day for most individuals is adequate for hydration
 - Adequate whole-body exercise and activity
 - Pelvic floor muscle exercise
 - Dietary measures can be augmented with natural bulk supplements like psyllium hydrophilic mucilloid (Metamucil®) and a stool softener such as docusate (Colace®)
 - Polyethylene glycol 3350 (Miralax®) is a laxative that can be taken safely on a regular basis. It is a works osmotic laxative that works by drawing water into the stool, softening it and making it easier to pass
 - Glycerine suppositories, inserted rectally, can help to soften the stool
 - Magnesium hydroxide (Milk of Magnesia®) is considered a gentle laxative and also works by drawing more water into the bowel
 - Enemas should be avoided, unless under the direction and care of a health care professional as they can lead to rectal injury, dependency and increase constipation
 - Constipation can cause other symptoms to flare:
 - Spasticity
 - Pelvic floor muscle dysfunction
 - Urinary symptoms
 - Sexual dysfunction symptoms
 - Pelvic pain
 - Fatigue
 - Weakness

- Bowel incontinence caused by spasms of the involuntary muscles of the bowel, pelvic floor muscle dysfunction and/or decreased sensation in the rectal area, is best managed with dietary measures, consistent bowel regimen, pelvic floor muscle exercises and conservative medical management such as pelvic floor physiotherapy. Anticholinergic medications – that are usually used to reduce bladder spasticity, may be helpful, but require careful monitoring of bladder function.
- Incontinence of loose stool may also be the result of infection or a side effect of a medication. Prolonged constipation can also lead to bowel incontinence since the impaction, or stool blockage, allows looser stool from higher in the digestive tract to leak out around the impaction.

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

What is the best way to talk to 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 counseling if necessary.

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

- Most people are relieved to know that their bladder and/or bowel problems are 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 experiencing in order not to be told to catheterize. However, most patients who try it find it to be an easy, convenient and life-changing form of self-care.
- Some spouses/partners of severely disabled individuals are willing and able to provide the necessary assistance with catheterization while others are not. If, in spite of information about the importance of intermittent catheterization and emotional support in the form of counseling, 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.] A clear understanding of the increased risks associated with an indwelling catheter may provide the necessary motivation.

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. While it may not always feel like it, their actions will impact the rate and development of bladder, bowel and sexual symptoms. Strategies including healthy dietary, lifestyle and toileting behaviors and proper exercise can make a significant impact in improving symptoms.
- Remind them that they are not alone and encourage participation in a support group or conversations with a peer counselor.
- Recommend individual counseling with a therapist who is familiar with MS.

When might surgical interventions be required to manage bladder problems?

- Surgical intervention may be needed if:
 - Adequate bladder control is not achieved with some combination of dietary and lifestyle modification, pelvic floor physiotherapy, ISC, anticholinergic or antimuscarinic medications, and antispasticity agents.
 - The person is unable to tolerate an indwelling catheter.

What other resources are available on this topic?

- The National MS Society offers information, resources and support for individuals with MS and their families, as well as resources for healthcare professionals.
 - MS Navigators (1-800-344-4867) provide information, referrals to healthcare providers in the community and support.
- Educational materials on a wide range of topics are available for your patients at no charge by calling an MS Navigator or at [nationalmssociety.org/brochures](https://www.nationalmssociety.org/brochures).
 - Controlling Bladder Problems in MS
 - Urinary Dysfunction and Multiple Sclerosis—Consumer Guide
 - Surgical Management of Bladder Dysfunction in Multiple Sclerosis
 - Understanding Bowel Problems in MS
 - Controlando los Problemas de la Vejiga en la Esclerosis Múltiple
- The National MS Society website ([nationalmssociety.org](https://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.

- Recommended reading
 - Holland NJ, Halper J (eds.). *Multiple Sclerosis: A Self-Care Guide to Wellness* (2nd ed.). New York: Demos Medical Publishing, 2005.
 - Kalb R (ed.). *Multiple Sclerosis: The Questions You Have; The Answers You Need* (5th ed.). New York: Demos Medical Publishing, 2012.
 - Kalb R, Costello, K, Giesser, B. *Multiple Sclerosis for Dummies* (2nd ed.). Hoboken NJ: Wiley Publishing, 2012
 - Schapiro RT. *Managing the Symptoms of Multiple Sclerosis* (6th ed.). New York: Demos Medical Publishing, 2014

About the authors

Nancy Holland, RN, EdD worked in the field of MS for more than 30 years, first as part of an interdisciplinary MS care team center at Albert Einstein College of Medicine providing comprehensive nursing care to people with MS, and then leading efforts to educate and support patients, families and healthcare providers in her work at the National Multiple Sclerosis Society. Dr. Holland 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*. Dr. Holland is also co-author of *Multiple Sclerosis for Dummies*. 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.

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Other resources for
Talking with Your MS Patients include:

Cognitive Dysfunction
Diagnosis of Multiple Sclerosis
Progressive Disease
Elimination Problems
Sexual Dysfunction
Depression and Other Emotional Changes
Initiating and Adhering to Treatment with Injectable Disease Modifying Agents
Family Issues
Reproductive Issues
The Role of Rehabilitation
Life Planning
Primary Progressive MS (PPMS)
Palliative Care, Hospice and Dying
Wheeled Mobility



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