

Society

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) 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 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. 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 and
   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 the National MS Society (1-800-344-4867) or the Society's website (www.nationalMSsociety.org/Bladder; www.nationalMSsociety.org/Bowel) 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?

- 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 National MS Society for these materials, will reinforce 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, 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 and other fluids.
- 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 three categories:
  - Failure to Store: As a result of damage in the central nervous system, small amounts of urine in the bladder cause uninhibited bladder contractions that 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 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 of the need to relax and release the urine. The urine remains in the bladder, which continues to fill and expand.
- Combined Dysfunction (failure to store and empty): Due to damage in the central nervous system, small amounts of urine in the bladder may trigger contractions and a strong urge to urinate. At the same time, the signal to the brain to release the bladder sphincter and empty the bladder is not received so that the bladder continues to fill and expand. This problem occurs because of lack of coordination between the muscle groups
- Because the three 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.
- Management strategies for the three types of dysfunction differ somewhat:
  - Failure to Store is managed with:
    - Medication to relax the overactive bladder (e.g., anticholinergic agents such as imipramine (Tofranil), oxybutynin (Ditropan XL), and propantheline bromide (Pro-Banthine), or the antimuscarinic agents, tolterodine (Detrol), solifenacin succinate (Vesicare), or trospium chloride (Sanctura)). Patients need to be told that these medications can

- cause dry mouth and increase constipation.
- Behavioral 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 absorbant pad for added security)
- Desmopressin acetate (DDAVP) can be used at night to help with nocturia (with periodic monitoring of electrolytes).
- Botulinum toxin, which is not FDAapproved for use in MS, has been used successfully in some people to manage storage problems.
- 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 or with a peer counselor) can reduce the person's anxiety.
  - If ISC does not eliminate symptoms, antimuscarinic or anticholinergic medications can be added. An antispasticity agent such as baclofen (Lioresal) may be 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.
- Combined Dysfunction is managed with:

- ISC to prevent a buildup of urine in the bladder
- Medication, if necessary, including anticholinergics to block acetylcholine in the central nervous system; antispasmodics to reduce painful muscle spasms; medications to promote urine flow; botulinum toxin.

#### 5. Are pelvic floor exercises beneficial for urinary dysfunction?

 Pelvic floor exercises, also known as Kegel exercises, may be helpful for both women and men in strengthening the muscles used in holding and expelling urine. These same exercises—which consist of alternately contracting and relaxing the muscles used to stop the flow of urine may also help promote a more satisfying sexual experience, as some of the same muscles used during intercourse are affected by the exercises.

# 6. 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).
- 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.

# 7. 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 lifetime 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 (generally 20 minutes after breakfast)
  - A high-fiber diet 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 or other fluids per day
  - Adequate exercise
  - Dietary measures can be augmented with natural bulk supplements like psyllium hydrophilic mucilloid

- (Metamucil) and a stool softener such as docusate (Colace).
- If necessary, magnesium hydroxide (Milk of Magnesia) or a glycerin suppository may be used.
- A docusate stool softening laxative (Enemeez Mini Enema) or sodium phosphate enema (Fleet) can be used if the other measures are insufficient.
- Regular use of enemas is to be avoided since they can lead to dependency and increase constipation.
- Constipation can cause other symptoms including spasticity and urinary problems to flare.
- 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.

#### 8. 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 patients can take
- home and read
- Encouragement to call with any questions or concerns

# 9. 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 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.

# 10. 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 emotional support and education about the importance of intermittent catheterization, 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.

# 11. 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 or conversations with a peer counselor.
- Recommend individual counseling with a therapist who is familiar with MS.

#### 12. 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 counseling to deal with feelings of grief, failure, and/or loss of self-esteem.

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

- The National MS Society has created educational materials on a wide range of topics. Your patients can obtain the following materials at no charge (1-800-344-4867) or in the Library section of the website at www.nationalMSsociety.org/ Brochures:
  - Controlling Bladder Problems in MS
  - Urinary Dysfunction and Multiple Sclerosis
  - Surgical Management of Bladder Dysfunction in Multiple Sclerosis
  - Understanding Bowel Problems in MS
  - Controlando los Problemas de la Vejiga en la Esclerosis Múltiple
- A variety of education and support programs are available through each National MS Society chapter.
- Counseling by a therapist familiar with MS can help individuals and families cope more comfortably with MS-related symptoms, particularly those that challenge feelings of confidence, selfesteem, and independence. National MS Society chapters can provide names of therapists with expertise in MS.
- National MS Society website
   (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.

- Bladder management http://www.nationalMSsociety.org/ Bladder
- Bowel management http://www.nationalMSsociety.org/ Bowel
- Sexuality and intimacy http://www.nationalMSsociety.org/ Intimacy

#### Additional recommended websites:

- Multiple Sclerosis Society of Canada www.mssociety.ca
- International Federation of Multiple Sclerosis Societies/ The World of Multiple Sclerosis http://www.msif.org/

#### Recommended readings:

- 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:
   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.
- Schapiro RT (ed.). Managing the Symptoms of Multiple Sclerosis (5th ed.).
   New York: Demos Medical Publishing. 2007.

Nancy Holland, RN, EdD, a recognized expert in clinical aspects of MS, served for many years as Vice President of Clinical Programs at the National MS Society in New York City, with a primary focus on professional education. She earned a doctorate in higher and adult education from 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 International Organization of MS Nurses (IOMSN), and served as the first chair of the IOMSN Research Committee.

Rosalind Kalb, PhD, is Vice President of the Professional Resource Center at the National Multiple Sclerosis Society in New York City, providing educational materials and consultation services for healthcare professionals. Dr. Kalb has authored or edited a number of National MS Society publications—the *Knowledge is Power* series for newly-diagnosed patients and the Cavallo Professional Education book series for health professionals. She has edited two books—*Multiple Sclerosis: The Questions You Have; The Answers You Need*—now in its 4th edition—and *Multiple Sclerosis: A Guide for Families*, now in its third edition. She is the senior author of *Multiple Sclerosis for Dummies*, and co-author with Dr. Nicholas LaRocca of *Multiple Sclerosis: Understanding the Cognitive Challenges*.

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