

A stylized, grayscale illustration of a human figure from the waist up, with arms raised and hands open. The figure is composed of various shades of gray, creating a layered, geometric effect. The background features abstract, curved lines and overlapping shapes, suggesting movement and light.

2015 NORTH AMERICAN EDUCATION PROGRAM

MANAGING
**BLADDER &
BOWEL ISSUES**
IN MS

DISCUSSION GUIDE
INCLUDING FREQUENTLY
ASKED QUESTIONS



National
Multiple Sclerosis
Society



INTRODUCTION

Welcome to the 2015 North American Education Program: **Managing Bladder & Bowel Issues in MS**, brought to you by the National MS Society in partnership with the MS Society of Canada.

People with multiple sclerosis (MS) may find that bladder and bowel symptoms prevent them from fully interacting with their community, friends and family. They may feel embarrassment about such symptoms, or erroneously assume that bladder and bowel changes are related to normal aging—or even that nothing can be done. As a result, MS-related bladder and bowel symptoms may go unaddressed, diminishing confidence and personal independence, and perhaps leading to other health issues and social isolation.

It needn't be that way. Once diagnosed, these common MS symptoms are in fact quite manageable and treatable, with the potential to profoundly improve quality of life and, ultimately, overall health.

We appreciate you taking the time to be a part of this important opportunity to help people address their bladder- or bowel-related symptoms and ultimately live better with MS.

We are pleased to have the following doctors and researchers as this year's program presenters:

Kelli Berzuk, BMR-PT, MSc, PhD
Nova Physiotherapy

Ellen Mowry, MD
Johns Hopkins Medicine

Matthew Durst, MA, PT
Saint Francis Hospital and
Medical Center

Marlene Murphy, MD
Joyce D. & Andrew J. Mandell
Center for MS Care and
Neuroscience Research

Pat Kennedy, ANP, MSCN
Can Do MS

Scott Newsome, MD
Johns Hopkins Medicine

We'd also like to thank the following individuals for so graciously giving their time and sharing their stories with us: Michael Mohn, Joan Molans Wood, Angel Muñoz Jr.

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RESOURCES

The National MS Society has an extensive library of resources about MS, including information about treatment options, symptom management, and facing the day-to-day challenges of living with this disease. For more information please contact an MS Navigator at 1-800-344-4867, contactusnmss@nmss.org, visit www.nationalMSSociety.org **Symptoms and Diagnosis** or **Living Well with MS** sections, or www.MSconnection.org.

PROGRAM SURVEY

The National MS Society strives to provide information, resources and programs that are relevant and important to people living with MS. Your feedback, and that of your group, is vital. We want to know what is important in your lives and what you consider to be critical programming. Please complete a short online survey at <https://www.surveymonkey.com/r/bladderbowel> or fill out one of the enclosed surveys. Mail all completed hardcopy surveys—using the enclosed addressed envelope—to:

National MS Society attn. Doris Lill
Broadway Station
900 S. Broadway, Suite 200
Denver, CO 80209

DISCUSSION

If you're considering bringing in a speaker, talk to your Society staff liaison about finding or coordinating a neurologist, urologist, physical therapist, nurse practitioner or MS-certified nurse.

The 35-minute video shares personal stories of people living with MS and their experiences managing bladder and bowel symptoms. Medical experts explore

the causes and science behind these symptoms, how they interact, treatment options, and exciting research into new treatments. The video can be watched in its entirety or broken up into two parts; the bladder chapters run 25 minutes and the bowel chapters run 10 minutes.

Please provide each participant with the companion book, which goes into more detail than the video, allowing you to delve deeper into the topics. If any participant would like to watch the video again, they can request a DVD by calling 1-800-344-4867 or watch online at www.nationalMSSociety.org/videos.

Discussion questions are provided to help facilitate conversation with your group after watching the video. For help with any questions that may arise, please utilize the list of frequently asked questions (FAQs) in this guide. These questions are not all-inclusive. Please refer unanswered questions (or questions that are outside the scope of the presentation) to an MS Navigator at 1-800-344-4867 or contactusnmss@nmss.org, or to one's healthcare team.

Suggested Group Discussion Questions:

1. How did you first recognize you were having issues with your bladder or bowel?
2. How did that make you feel?
3. How long did it take before you discussed this issue with your doctor and healthcare team? If you haven't, why not?
4. Have you discussed what you were experiencing with your family and friends?
 - a. If no, why not? If yes, how did they respond?
 - b. How did you explain what was going on?
5. Have your bladder and bowel symptoms affected your family? If yes, how?
6. Do you find these symptoms more difficult to discuss than other MS symptoms? Why?
7. What strategies have you used to manage bladder or bowel issues?
8. What resonated with you from this video?

FREQUENTLY ASKED QUESTIONS (FAQs)

What is the prevalence of bladder and bowel symptoms in MS?

It's been reported that 70 to 90 percent of people with MS experience issues with elimination at some point in their disease course. In general, people with MS are much more likely to have difficulty with the lower urinary tract than with the upper. These symptoms are often referred to collectively as "bladder problems." Nearly 50 percent of people with MS report that bowel problems are significant enough to interrupt their work, social activities and other aspects of day-to-day life—at least some of the time.

Do bladder and bowel impact each other?

On the whole, people with MS experience problems with their bladders more often than with their bowels. But because the organs for urination and bowel evacuation are linked anatomically—they form sort of a figure eight in the pelvis—a problem in one system often leads to a problem in the other, so they have to be addressed together.

What types of bladder problems occur in MS?

The most common problem involves overactivity of the bladder's detrusor muscle, which interferes with the storage of urine. Another type of bladder problem in MS involves impaired emptying. This happens when the demyelinated nerves in the spinal cord don't tell the brain that the bladder is full and needs to be emptied, and/or that the external sphincter should relax to allow urine to flow. As a result, the bladder keeps filling and stretching. Eventually, the bladder stretches too much, becoming overly relaxed and flaccid. Emptying problems can lead to reoccurring urinary tract infections (UTIs). The last—and least common—type of bladder problem seen in MS is combined dysfunction. Essentially, this is a storage problem and an emptying problem happening at the same time. Depending on the type of bladder issue, the specific symptoms will vary and may overlap.

How do bladder problems associated with MS differ from problems associated with aging or childbirth?

You may erroneously assume your symptoms are merely a sign of growing older, or related to childbirth, and nothing can be done about them. The central nervous system (CNS) damage that occurs in MS can also produce bladder and bowel

symptoms. Damage to the myelin on nerve fibers (demyelination) can disrupt the transmission of signals between the brain and the urinary system and intestines. Bladder and bowel symptoms are among the most successfully treated aspects of MS.

Why is it critical to diagnose bladder problems?

Bladder problems, if left unmanaged, can escalate and cause a host of other medical problems, such as infections, depression, skin breakdown, kidney stones and other kidney problems. Bladder issues can also interfere with sleep, social activities and work.

How can unmanaged bladder changes worsen overall health?

Bladder problems can take a toll on other aspects of physical health. These may include bowel problems, sexual dysfunction, skin issues, sleep disturbances, dehydration, kidney stones and falls.

What treatment options are available to manage bladder issues?

- Lifestyle modifications including dietary changes and smoking cessation
- Pelvic exercise and pelvic floor rehabilitation
- Medications including:
 - Botox[®]
 - Ditropan[®]
 - Cardura[®]
 - Detrol[®]
 - Desmopressin acetate
 - Enablex[®]
 - Flomax[®]
 - (Hytrin[®] in Canada)
 - Gelnique[®]
 - Lioresal[®]
 - Myrbetriq[®]
 - Oxytrol[®]
 - Pro-Banthine[®]
 - Rapaflo[®]
 - Toviaz[®]
 - Urispas[®]
 - Uroxatral[®] (United States only)
 - VESIcare[®]
 - Zanaflex[®]
- Catheterization
- Nerve stimulation
- Surgery

What types of bowel problems occur in MS?

The most common bowel issue reported among people with MS is constipation. Other bowel problems that may affect people with MS include urgency, impaction and loose stool or involuntary bowel movements.

What causes bowel problems in MS?

A number of MS-related factors can contribute to bowel problems including:

- Bladder problems
- Limited mobility
- Nerve damage
- Weak or spastic muscles
- Inadequate fiber and fluid in the diet
- Medications
- Impaction
- Reduced sensation in the rectal area
- Bowel habits

What treatment options are available to manage bowel issues?

The first step in treating bowel issues is to establish good bowel habits, including dietary changes, staying active and setting a schedule. If lifestyle modifications don't fully solve bowel issues, certain over-the-counter (OTC) or prescription medications may be recommended by the physician. These include stool softeners, laxatives, suppositories and enemas. Beyond medications, additional therapies may help including manual stimulation, pelvic floor therapy and sacral nerve stimulation.

How do bladder and bowel problems affect those around you—and daily life?

You may avoid certain professional or social situations—even with close friends or family members—for fear of having an “accident,” or requiring too many trips to the bathroom. This kind of avoidance can lead to isolation, reduced confidence and self-esteem, and loss of independence.

How are bladder and bowel problems diagnosed?

The first thing your provider will probably do is get a detailed history of your bladder and or bowel symptoms. Because bladder and bowel symptoms impact each other and are closely related, one of the first steps in diagnosing a bowel problem will be to rule out any bladder issues.

In diagnosing a bladder issue, the next step will likely be to test for a possible urinary tract infection (UTI). If the test is negative, your doctor or other healthcare provider will probably want to conduct additional tests. These might include post-void residual (PVR) testing, urodynamics and a kidney ultrasound.

If bladder issues have been ruled out, then a series of additional testing will be done to identify the cause of bowel problems. A clinical exam will be done followed by additional testing such as a colonoscopy, abdominal X-rays, anorectal manometry and a defecography or dynamic proctography.

Based on the results of these tests, your healthcare provider will be able to recommend the best approach to treating your symptoms.

What role does diet and exercise play in bladder and bowel issues?

Often, symptoms can be helped by simply adjusting your diet and your fluid intake. You might be advised to limit caffeine, alcohol, artificial sweeteners, and citrus juices since those can irritate the bladder and worsen storage problems. Smoking is also a bladder irritant. Staying hydrated will help flush out waste and bacteria, keep your urine from becoming so concentrated that it irritates the bladder, and help keep your digestive system from becoming constipated as a result. Increasing fiber and staying active can also help with bowel issues.