A stylized human figure composed of various colored segments (blue, green, yellow, purple) is shown in a dynamic, forward-leaning pose. The figure is set against a background of light blue and green wavy bands and thin curved lines. The overall aesthetic is modern and energetic.

2015 NORTH AMERICAN EDUCATION PROGRAM

# MANAGING BLADDER & BOWEL ISSUES IN MS



National  
Multiple Sclerosis  
Society





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- Joyce D. & Andrew J. Mandell Center for Multiple Sclerosis Care and Neuroscience Research, Hartford, Connecticut
- Nova Physiotherapy Women's Health Centre, Winnipeg, Manitoba, Canada

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 Muñiz Jr.

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

People with multiple sclerosis 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 these individuals' 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.

In the video portion of this program, you will hear discussions about the latest advances and recommendations, both from clinicians at the forefront of MS research and treatment, as well as from individuals who have experienced these symptoms and have insights to share.

This booklet provides an overview of the types of bladder and bowel issues common to MS. It further outlines the most successful ways that individuals and clinicians have developed for managing these symptoms, and explains why doing so is of utmost importance to your general well-being. At the back of this booklet, you'll find resources for learning even more about these topics.

We hope you will find the program informative and engaging. For further information, call 1-800-344-4867 (U.S.) or 1-800-268-7582 (Canada), or visit **[nationalMSSociety.org](http://nationalMSSociety.org)** or **[mssociety.ca](http://mssociety.ca)**.

Best regards,

**Kay Julian**

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# INTRODUCTION

Multiple sclerosis is an unpredictable, often disabling disease of the central nervous system (CNS), which is composed of the brain, spinal cord and optic nerves. MS is believed to develop when the immune system malfunctions and targets the CNS. This malfunctioning causes inflammation and damage to myelin (the sheath that insulates the nerves) and to the underlying nerve fibers. As a result, MS interrupts the flow of information within the brain, and between the brain and the rest of the body. This damage causes the many symptoms that are commonly associated with MS, such as limb weakness, spasticity and vision problems.

The CNS damage that occurs in MS can also produce bladder and bowel symptoms. In fact, bladder and bowel issues in MS are wide-ranging—and common. It's been reported that 70 to 90 percent of individuals with MS experience issues with elimination at some point in their disease course.

Just because they're common, however, doesn't mean such problems are easy to live with. People 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. Over time, this kind of avoidance can lead to social isolation, reduced confidence and self-esteem, and a loss of independence. People may stop participating in many of the activities that they find satisfying and enjoyable.

People may erroneously assume that their symptoms are merely a sign of growing older and that nothing can be done about them. What's more, our culture can make people feel that it's taboo to discuss bladder and bowel symptoms openly, even with their physicians. For these and other reasons, people may be reluctant to seek treatment. When left untreated, however, bladder and bowel symptoms can lead to significant complications and seriously compromise an individual's health and well-being.

The good news is that bladder and bowel symptoms are among the most successfully treated aspects of MS. The first step is to have a candid conversation with a physician—who can address these concerns in a matter-of-fact manner. He or she will work to identify the specific types of issues that are occurring, and then will be able to prescribe treatments, ranging from simple diet and lifestyle modifications to medications or possible surgical approaches.

Most people find that when they have their bladder and bowel issues under control, they're able to return to their lives—fully engaged and in charge.

# PERSONAL STORIES



**MICHAEL MOHN**  
**DIAGNOSED WITH MS IN 2005**

Michael lives with his wife, Kristie, in Forest Hill, Maryland, and works at Johns Hopkins Medical Center. Michael enjoys spending time on his boat and attending sporting events with his children. A motorcycle enthusiast, Michael also enjoys getting out on the road with his friends. Michael says self-catheterization has helped him resume a normal life.



**JOAN MOLANS WOOD**  
**DIAGNOSED WITH MS IN 2000**

Joan lives in East Hartford, Connecticut with Tommy, her husband of 12 years. After her MS-related bladder problems worsened, Joan and her physician discussed surgical options. Two weeks after undergoing a urinary diversion surgery, Joan was able to enjoy the freedom of going out with friends to watch a Broadway show—without a backpack full of supplies. Joan also enjoys relaxing at home with her husband, as well as occasional road trips with friends.



**ANGEL MUÑIZ JR.**  
**DIAGNOSED WITH MS IN 2002**

Angel lives in Newington, Connecticut, with his mother and stepfather. Angel enjoys working out, volunteering at his church and spending time with his siblings, niece and nephew. Angel credits his renewed social life to successful treatment of his bladder and bowel issues.

## PRESENTERS

### **Kelli Berzuk, BMR-PT, MSc, PhD**

Dr. Kelli Berzuk is a pelvic floor physiotherapist and the owner and founder of the Incontinence & Pelvic Pain Clinic, a division of Nova Physiotherapy, in Winnipeg, Manitoba. For over 20 years, her clinical practice has specialized in pelvic floor dysfunction and the treatment of bladder, bowel and sexual dysfunction, as well as pelvic pain, and pelvic organ prolapse. She received her postgraduate pelvic floor education through the American Physical Therapy Association, and has certification in pelvic floor rehabilitation and continence from the University of Melbourne, Australia. She received her Bachelor of Medical Rehabilitation (physical therapy) degree, as well as a Master of Science degree and a PhD in urogynecology from the University of Manitoba.

### **Matthew Durst, MA, PT**

Matthew Durst is a physical therapist who has developed a clinical specialty in pelvic floor rehabilitation over the past 15 years. He received a liberal arts degree from Villanova University before achieving a combined Bachelor of Science/Master of Arts degree in physical therapy from Touro College in New York City. He currently practices at Saint Francis Hospital & Medical Center in Hartford, Connecticut.

### **Pat Kennedy, ANP, MSCN**

Pat Kennedy has been working in the field of MS since 1987. Initially she worked as a nurse practitioner in a large comprehensive MS center and then worked for Can Do Multiple Sclerosis as a nurse educator for staff and community, and as program adviser for the organization. She retired in 2015 but continues as a programs consultant for Can Do MS. She is certified as an MS nurse.

### **Ellen Mowry, MD**

Dr. Ellen Mowry became interested in MS prior to beginning college. As a neurology resident at the University of Pennsylvania, she began her MS clinical research activities in a study of visual dysfunction and quality of life. As a fellow at the University of California-San Francisco, Dr. Mowry evaluated prognostic factors and examined health-related quality of life in MS, particularly as a marker of disease burden. She continued as a member of the UCSF faculty, where she explored the association of vitamin D status with the risk of relapses among children with MS, and was subsequently awarded a grant from the National Institutes of Health to study the role of vitamin D in the course of MS. Dr. Mowry is currently the Associate Professor of Neurology and Epidemiology at the Johns Hopkins Department of Neurology. In addition to conducting ongoing studies, she is launching a multicenter randomized controlled trial of vitamin D supplementation in MS and was recently awarded the National MS Society's Harry Weaver award to study calorie restriction in MS.

### **Marlene Murphy-Setzko, MD**

Dr. Marlene Murphy-Setzko is a urologist, a physician specializing in treating conditions affecting the urinary tract in men and women, including neurogenic bladders, voiding dysfunction, and incontinence. She is the director of urologic services at the Joyce D. & Andrew J. Mandell Center for MS Care and Neuroscience Research in Hartford, Connecticut. At Mandell, she served on a clinical committee that developed urology guidelines specific to MS in a comprehensive care center. She also is lead urologist at the Curtis D. Robinson Men's Health Institute at Saint Francis Hospital and Medical Center in Hartford, and associate professor of surgery at the University of Connecticut. Dr. Murphy's recent research has focused on the correlation between disability and bladder/bowel dysfunction in people with MS, as well as on the sexual satisfaction of individuals with MS.

### **Scott Newsome, DO**

Dr. Scott Newsome is a neuroimmunologist specializing in the care of patients with MS. His research focuses on the development of clinical outcome measures and imaging techniques to improve the precision of disability assessments in MS and other central nervous system disorders. Dr. Newsome completed a fellowship in neuroimmunology at The Johns Hopkins Hospital with the support of a Sylvia Lawry Physician Fellowship from the National Multiple Sclerosis Society, and he continues to practice at Johns Hopkins.

An abstract graphic design featuring two stylized arms reaching out from the top right. The upper arm is green and the lower arm is blue. The background is a complex composition of overlapping, semi-transparent geometric shapes in various shades of blue, green, yellow, and purple. The overall aesthetic is modern and clean.

# **BLADDER HEALTH**

## THE BASICS

It's easy to take bladder function for granted. After all, most people have been successfully managing it since toddlerhood with nary a thought. But the successful elimination of waste products from the body relies on the precise coordination of more than a half-dozen anatomical structures. When MS interferes with that coordination, urination takes on a new level of complexity. To operate optimally, the structures must all work properly. See the diagram on page 9.

When everything is working smoothly, urine slowly collects in the bladder, causing it to expand, much like a balloon filling with water. While the detrusor muscle stretches to hold the urine, the internal sphincter contracts to prevent the leakage of urine from the bladder to the urethra.

Once the bladder contains about 8 ounces of urine, special sensors called stretch receptors send messages to the brain (via the spinal cord) that it's time to empty. Then the opposite process begins: The brain tells the detrusor muscles to contract, and the internal sphincter to relax. The urine begins to flow into the urethra. This is known as the "voiding reflex."

When that happens, the external sphincter muscle tightens, creating the urge to urinate. Once a person feels the urge and decides when and where to urinate, he or she relaxes the external sphincter, and urine flows out of the body.

"A normal range of needing to void would be about five to nine times a day and zero to one time at night," says Kelli Berzuk, PhD, a pelvic floor physiotherapist and the owner and founder of the Incontinence & Pelvic Pain Clinic, a division of Nova Physiotherapy, in Winnipeg, Manitoba.

In MS, however, these processes don't always work so harmoniously. Damage to the **myelin** on nerve fibers (demyelination) can disrupt the transmission of signals between the brain and the urinary system.

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," even though the urethra and sphincters may also be affected.

Even though bladder problems are common among people with MS, they are NOT inevitable, and should be addressed as early as possible. "It's not a normal part of aging," says Dr. Berzuk. While people with MS "have so many other things that could

be not working properly, so they may have a little more risk of having bladder and bowel issues, but it doesn't need to be like that," she says. "If you don't seek assistance, it only gets worse," adds Matthew Durst, a physical therapist with a clinical specialty in pelvic floor rehabilitation at Saint Francis Hospital & Medical Center in Hartford, Connecticut.

In fact, bladder problems, 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.

Ask yourself the following questions:

- Do I get up more than one time a night to urinate?
- Do I urinate more frequently than I used to?
- Do I ever have to rush to the bathroom to avoid having an accident?
- Do I leak urine or have accidents?

If you answered "yes" to any of these, you may in fact have bladder dysfunction. (See the section on diagnosis on page 16 for more detailed information.)

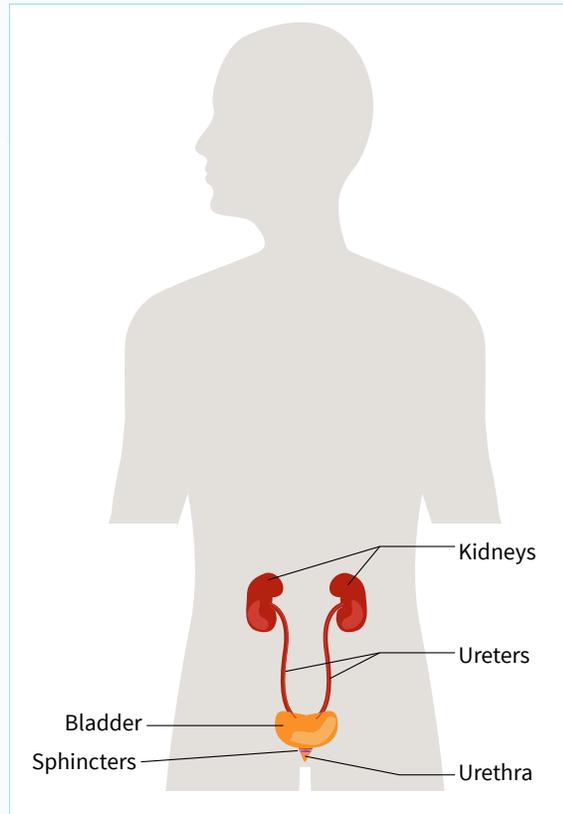
An increase in urgency was a big tip-off for Angel Muñoz Jr., who was diagnosed with MS in 2002. "About three years later, I was driving with my friends when I realized I needed to go, but I thought I could hold it. I couldn't and I went on myself," he says. After that point, he recalls, "Whenever I felt the urge, I couldn't hold it more than a couple of seconds." Muñoz, now age 35, notes that he began to avoid doing anything in public because his symptoms felt so unpredictable. For example, if he had a drink of water, he didn't know how long it would be before he needed to urinate. "I just had to always monitor where the nearest bathroom was, wherever I went. It wasn't a good experience."

In almost all cases—including Muñoz's—bladder problems can be successfully managed. However, it is essential to report bladder symptoms to your healthcare provider so that a comprehensive evaluation can be completed and you and your provider can work together to develop an effective treatment plan. Treatments range from simple lifestyle measures to medication, specialized physical therapy and, much less frequently, surgery. (See the section on treatment for more details.)

## UPPER URINARY TRACT

The main roles of the upper urinary tract are to remove waste from the bloodstream, and to keep the ratio of salt and water in the bloodstream in balance. This part of the system has two main components:

- **Kidneys:** The two organs in the abdominal cavity that remove impurities and water from the blood, resulting in urine.
- **Ureters:** Thin tubes—one leading from each kidney—that carry urine to the bladder.



**Urinary tract system**

## LOWER URINARY TRACT

The lower urinary tract's main functions are storing urine and emptying it. This part of the system has three main components:

- **Bladder:** A hollow, muscular pouch in the pelvic cavity that stores urine. The bladder wall has three layers – the mucosa, the submucosa and the **detrusor** muscle. The detrusor contracts to expel urine and expands to retain it. The bladder is about 2 inches long when empty, and expands to about 5 inches when full.
- **Urethra:** The tube that carries the urine from the bladder to the outside of the body.
- **Internal and external sphincters:** Circular bands of muscle fibers located between the bladder and urethra. The internal sphincter is controlled involuntarily and helps to keep the urethra closed, while the external sphincter can be relaxed and tightened consciously.

## BLADDER PROBLEMS IN MS

When MS-related lesions, or sites of damage in the brain and spinal cord, interrupt the nerve signals between the urinary tract and the brain, several types of bladder problems can occur.

The most common problem involves overactivity of the bladder's detrusor muscle, which interferes with the **storage** of urine. An overactive detrusor muscle begins to contract as soon as a small amount of urine has accumulated. This can happen repeatedly and, each time, the contractions signal the need to urinate. This can result in the following symptoms of "overactive bladder":

- **Frequency and/or urgency:** The sudden and intense urge to urinate, even if voiding occurred just minutes ago. Dr. Marlene Murphy-Setzko, the director of urologic services at the Mandell Center for MS in Hartford, Connecticut, says that with urgency, you feel like "you have to get there quickly." She defines frequency as having to go more than eight times in 24 hours. Together, urgency and frequency are the most commonly reported urinary problems related to storage.
- **Nighttime urgency (nocturia):** Frequent and urgent urination that occurs at night, leading to poor sleep, nighttime incontinence or both. Dr. Murphy considers a person to have nocturia if they get up more than twice per night to urinate.
- **Incontinence:** The inability to control when and where you urinate. This might involve emptying the whole bladder, or just leaking a few drops. Sometimes this occurs as an extreme form of urgency.

Symptoms of overactive bladder can become more common over time or as the severity of the disease progresses. "This is especially true in people whose symptoms, which have accrued over time, seem [related] to the spinal cord lesions," says Dr. Ellen Mowry, a neurologist specializing in MS at Johns Hopkins Hospital, and an assistant professor of neurology at Johns Hopkins University. "And since progressive MS often presents with worsening symptoms referable to the spinal cord or because of damage to the spinal cord, we often see more bladder (and bowel) problems in those individuals," she adds.

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. One or more of the following symptoms can then occur:

- **Urgency:** If an individual has reduced sensation, then the feeling of needing to urinate is delayed. An overly full bladder can trigger more contractions of the detrusor muscle, worsening any existing symptoms of urgency or incontinence.
- **Incomplete emptying:** Some urine is retained in the bladder even after urination (voiding). This is known as **post-void residual (PVR)**.
- **Dribbling:** The involuntary release of a small amount of urine that occurs when the bladder is overly full or after an incomplete emptying of the bladder.
- **Hesitancy:** If the external sphincter contracts instead of relaxing, it can be difficult to initiate a urine stream, or the urine stream may be a weak and intermittent trickle.

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. It occurs when the detrusor muscle and the sphincters are not coordinated. Even as small amounts of urine in the bladder trigger muscle contractions and a strong urge to urinate, the brain fails to receive the signal, so the bladder does not empty. Any of the symptoms described above can result from this combined dysfunction.

## BLADDER AND OVERALL HEALTH

Despite its relatively small size, the human bladder can have a big impact on overall health and quality of life. More than just a physical problem, bladder dysfunction can take a toll on emotional, social and vocational aspects of a person's life. It may even lead to a worsening of MS symptoms and disability. Here's how:

**Infections.** People who have trouble emptying their bladder will retain small amounts of urine in it. That can lead to the growth of bacteria and mineral deposits, ultimately resulting in kidney stones, bladder infections or **urinary tract infections (UTIs)**. People who have a UTI may have some or all of the following symptoms:

- Urgency
- Frequency
- Burning sensation while urinating
- Pain in the abdomen or lower back
- Fever
- Increased muscle spasticity
- Dark or foul-smelling urine

In addition to these symptoms, an untreated UTI can lead to kidney damage and life-threatening health problems. "If bacteria are sitting in the bladder too long, [the infection] can creep up and affect the kidneys. It can also seep into the blood stream," which can ultimately be fatal, says Dr. Scott Newsome, a neuroimmunologist at Johns Hopkins Hospital in Baltimore.

Sometimes, people with MS may not notice symptoms of a UTI, such as burning or pain when urinating, because they have sensory loss. "So a person with MS may carry this infection for a while longer than someone else who has full sensation," says Patricia Kennedy, an MS nurse and program consultant for Can Do MS. "So when they finally discover it, they're going to be sicker." Therefore, it's especially important to be alert to any other changes that might signify a UTI, such as changes in the color and smell of urine.

It's also important to be on the lookout for increases in MS symptoms, such as visual disturbances, cognitive changes, pain, weakness and spasticity. These worsening symptoms can be caused when an infection raises a person's core body

temperature, creating a condition known as a **pseudoexacerbation**. Usually, this type of temporary flare-up or relapse resolves once the infection is treated.

It's important for individuals with MS and their physicians to know whether they are experiencing a true relapse or if their symptoms have worsened due to an infection. If it's a true relapse, the most common treatment is with steroid medications. However, giving steroids to a person with an active infection could actually worsen the problem.

Dr. Ellen Mowry, an assistant professor of neurology and epidemiology at Johns Hopkins School of Medicine, is completing a National MS Society-funded study that is examining the possible role of UTIs in MS relapses, as well as their role in the temporary worsening of MS symptoms (called pseudoexacerbations) that can be caused by infections. Once the study is concluded, the results could provide valuable information to doctors about how to interpret and manage the symptoms that their patients report—and could even empower patients to assist in their own diagnosis by answering a series of specific questions and testing urine samples at home.

In any event, it's important for people with MS to remain alert to any changes in their bladder health and report them immediately to their physician. As Dr. Murphy notes, “With each infection, you might be taking a step back,” relative to your MS and your overall level of health and functioning. Getting treated can help minimize any setbacks caused by the infection.

**Other physical complications.** Bladder problems can take a toll on other aspects of physical health. These may include:

- **Bowel problems:** The bladder and bowel are very near each other in the body, so a problem in one area often affects the other. “If you have a very full bladder, for example, that actually pushes on the colon and rectum, and that can cause constipation,” notes Dr. Newsome.
- **Sexual dysfunction:** People who have problems with their bladder are more likely to experience changes in sexual function as well because those functions involve the same area of the spinal cord. Bladder problems can sometimes interfere with intimacy because people become concerned about loss of bladder control or accidents during sexual activity.
- **Skin issues:** Repeated exposure to moisture can cause skin irritation and wounds. This is even more likely for people with limited mobility, as pressure from a wheelchair or bed can aggravate the problem.

- **Sleep disturbances:** Bladder dysfunction can affect sleep, if urinary urgency and frequency cause people to awaken during the night. “That can lead to increased fatigue, which is already a major problem for many people living with MS,” notes Dr. Mowry.
- **Dehydration:** People who avoid drinking water to limit the number of times they need to urinate may find themselves chronically dehydrated, leading to further complications such as constipation and worsening of heat-related symptoms. “If you’re dehydrated it can also make it harder to exercise and carry out your activities,” and can also cause headaches, Dr. Mowry says.
- **Kidney stones:** Painful kidney stones may occur more frequently in people with MS-related bladder issues, particularly if fluid intake is restricted.
- **Falls:** Sometimes, people with bladder issues try to hurry to the bathroom (or rush to transfer to the commode) to avoid accidents, even though they may have gait problems. This can increase the risk for falls and injury.

That happened to Muñiz, who says that he has weakness in his legs and his right foot often drags, “and that was the reason why, at times, I couldn’t go to the bathroom when I felt it—because either I tripped, or by the time I got enough strength to stand up, it was already too late.” Getting his bladder issues treated, he says, means that “Now I feel like I don’t have to rush.”

The link between gait difficulties and bladder issues is one that’s currently being researched. A small pilot study by occupational therapist Tracy Flemming Tracy and Dr. Emily Riser, both of the Tanner Center and Foundation for Multiple Sclerosis in Birmingham, Alabama, examined the relationship between bladder dysfunction and overall walking speeds in MS. They enrolled 34 people who were newly diagnosed with MS (within the previous year) and found that 38 percent of them retained urine in their bladders immediately after going to the bathroom. The researchers also found that of these people with post-void residual (PVR), 100 percent also had slower than normal walking speeds, and a third showed significant impairment in walking speed. The researchers concluded that early detection and treatment of bladder problems could help reduce further disability by reducing the risk of infection and worsening of MS symptoms.

**Challenges to social, family and work relationships.** Untreated bladder problems can lead to social isolation, as people avoid leaving their homes or participating in once-enjoyable activities for fear of not being able to access bathrooms as easily

or frequently as they would like. “Research shows us that people’s worlds become smaller when they’re experiencing bladder and bowel dysfunction,” says Dr. Berzuk.

“It definitely affected my social life,” says Michael Mohn, age 51, who was diagnosed with MS in 2005. “I love going to sporting events, and it definitely made me think twice when I was invited to go because it’s hard to get to a restroom there. The lines are long, and it would get to the point where I wouldn’t be able to use the restroom when I needed to. It made me isolate myself sometimes, too ... I would keep to myself at home, where I knew I could use the restroom.”

Bladder issues can take a toll on family members, too, who may grow annoyed at the need to plan activities around their loved one’s bathroom requirements. “I think in the best of couples and the best of relationships, that wears wrong sometimes and you see irritability around these topics because they are interrupting the normal way of things,” says Kennedy, the MS nurse.

Mohn found that to be true in a previous relationship. “She was embarrassed of me when I would have an accident. And when I couldn’t do something she wanted to do, she didn’t understand the difficulty I would have using the restroom. She got frustrated quite often.”

Dr. Murphy says that the impact on family members is often under-appreciated. In some cases, a spouse’s role changes from being an intimate partner to being a caregiver who now performs tasks such as laundering soiled clothing and assisting with toileting.

Bladder problems can also jeopardize work relationships. Repeated trips to the restroom may result in reduced productivity and poor performance, and perhaps resentment from co-workers. “It doesn’t look good in your workplace if you’re the one running to the washroom all the time,” Dr. Berzuk says. Mohn confirms this. “If I was going to a meeting or something, there were times when I just couldn’t get up and go to the restroom when I needed to,” he says.

Researchers concluded that early detection and treatment of bladder problems could help reduce further disability by reducing the risk of infection and worsening of MS symptoms.

**Loss of self-esteem and independence.** Ongoing bladder symptoms can be a source of significant distress. Consider that learning to control the bladder is one of the first things a young child learns to do; it's no wonder that adults feel embarrassment or even shame when they can no longer exert that same control. "I've always been a confident individual," Muñiz says. "And this really demolished a lot of things for me—not so much being diagnosed with MS, but now I have my bladder issue that I can't control." Muñiz adds, "The main reason why I spoke to my doctor is because I realized that I couldn't keep on living like this, being embarrassed, hiding myself away from the public. My doctor referred me to a urologist who helped me to understand that I wasn't going crazy, that this is a part of the MS, and that I needed to address this before it got any worse."

If the bladder symptoms go untreated, the physical and social impacts can lead to a higher degree of disability, and an inability for an individual to make his or her own life choices.

## DIAGNOSING BLADDER DYSFUNCTION

If you have noticed that you go to the bathroom more frequently than you used to, have to rush to the bathroom, or sometimes have accidents, you may already suspect issues with your bladder health. Some additional questions may help you and your doctor narrow down the problem. Ask yourself the following:

- Am I finding it more difficult to start urinating when I get to the toilet?
- Do I feel as though my bladder isn't completely empty when I've finished urinating?
- Do I experience frequent or recurring UTIs?
- Am I using pads or any other strategies to protect my clothing from possible leaks?
- Am I limiting the amount of fluids I drink because I worry about having to urinate so frequently?
- Am I planning my daily activities around my bladder symptoms?
- Do my bladder symptoms keep me from doing what I enjoy?
- If I had to spend the rest of my life with my bladder behaving the way it does now, would I be unhappy?

If you answered “yes” to ANY of these questions, it’s important to let your healthcare provider know right away. He or she can do some tests to get to the bottom of your symptoms, so that they can be successfully treated and you can get back to living your life.

The first thing your provider will probably do is get a detailed history of your bladder symptoms.

The next step will likely be to test for a possible UTI, which just involves getting a urine sample from you and testing it for the presence of bacteria. If the test does show a UTI, you’ll probably be treated with antibiotics.

If the test is negative, your doctor or other healthcare provider will probably want to conduct additional tests to determine what type of bladder dysfunction is causing your symptoms.

These might include **urodynamics**—an evaluation of your bladder function, which can show how your pelvic floor and bladder muscles work together in real time. Your provider may also check your kidneys by performing an ultrasound.

First, however, your provider may want to test whether you are retaining urine in your bladder. The test for post-void residual (PVR) is done in one of two ways. The first way is to insert a **catheter** (a thin, hollow tube) into the urethra after you urinate to drain and then measure any PVR. The second way is to perform an ultrasound of your bladder. Any amount of PVR less than 100 ml is considered normal.

If your PVR test—by either method—shows that you are retaining less than 200 ml, your provider will likely conclude that your symptoms are caused by an overactive detrusor muscle. If you are retaining more than 200 ml, it means that your symptoms are likely caused by problems with emptying.

In either case, your provider will discuss various treatment options with you.

# MANAGEMENT AND TREATMENT OF BLADDER DYSFUNCTION

The range of treatment options for bladder dysfunction is wide. The first line of treatment often involves simple lifestyle adjustments. In addition, there are medications, rehabilitation approaches, surgery and more.

There's no treatment that works for every person. Just as MS symptoms are different for each individual, so too are the management strategies that are effective for those symptoms. Here's an outline of the most commonly used methods of overcoming bladder symptoms in MS.

**Lifestyle modifications.** Often, symptoms can be helped by simply adjusting your diet and your fluid intake. You might be advised to limit caffeine, alcohol and artificial sweeteners, since those can irritate the bladder and worsen storage problems. If you're prone to UTIs, you might be advised to limit citrus juices; surprisingly, they make the urine more alkaline than acidic, encouraging the growth of bacteria. Smoking is also a bladder irritant, so if you do smoke, it's another reason to quit.

It's also critically important to drink enough water—enough so that your urine is light yellow. Often, people with bladder symptoms will restrict the amount of fluid they drink in an effort to prevent accidents. But if you don't drink enough, you risk becoming dehydrated, which makes urine so concentrated that it actually irritates the bladder and makes urgency and incontinence even more likely. Staying hydrated will also help flush waste, bacteria and mineral deposits from your bloodstream, helping you to avoid UTIs. "I always restricted my drinking," admits Joan Molans Wood, age 52, who was diagnosed with MS in 2000. "I know that it probably affected getting UTIs, because I've just recently had one."

Rather than restricting the amount you drink, time your fluid intake strategically: Avoid drinking within two hours of any activity that won't have bathroom breaks. Also limit your before-bed beverages, so that you're more likely to sleep without interruptions from your bladder.

Many people also find that they benefit from scheduled bathroom breaks. If you go to the bathroom every two hours or so during the day, you'll eventually train your bladder (and avoid overfilling it), lessening your chances of an accident.

It also helps to be prepared. It's wise to keep a stash of absorbent pads and a change of clothing on hand.

Although most bladder problems can be effectively managed, it may take time to find the optimal solutions.

"In many cases, just these little changes actually can help someone's bladder function enough so you don't even have to [turn] to medications," says Dr. Newsome.

**Pelvic exercise.** Like bootcamp for your bladder, pelvic floor exercises help tone the muscles that support the bladder, the uterus (in women), the prostate (in men) and the rectum. Strengthening and coordinating these muscles can vastly improve bladder function. "Because the pelvic floor muscle is under our active control, we can do a lot to help protect ourselves," Dr. Berzuk says.

The most well-known pelvic floor exercises are **Kegels**, in which an individual alternately contracts and relaxes the muscles that stop urine in midstream. Kegels can be performed by both women and men. Sometimes, however, performing Kegels may not be sufficient. It's also possible that an individual may not be doing Kegels properly, or in some circumstances, that they should not be doing them at all.

A physical therapist with specialization in the pelvic floor can help teach people with MS how—and when—to perform these and other exercises for **pelvic floor rehabilitation**. In addition to strengthening the pelvic floor muscles, the therapist may also focus on teaching people with MS how to actively relax their muscles, particularly if they have muscle spasticity, says Dr. Berzuk.

In one form of pelvic floor rehab, the therapist inserts a pelvic probe fitted with sensors (into the vagina for women and into the rectum for men), and then asks the individual with MS to contract and relax the pelvic muscles. As a form of biofeedback, the sensors display information on a computer screen so the individual and the therapist can see how well the muscles are being engaged. Then the individual can do these exercises at home. "The key component with this is really incorporating these exercises into everyday life," says pelvic floor therapist Matthew Durst. This type of treatment has been shown to be quite effective. In a 2007 study, people who used this technique saw a 76 percent average improvement in their symptoms of frequency, urgency and PVR. It's often covered by insurance, but people will need to check with their individual providers.

A pelvic floor therapist may also provide education on proper toileting posture. “Other physiotherapists would look at how you sit at your computer, but we want to know what you are actually doing when you’re on the toilet,” says Dr. Berzuk. For example, people who “hover” to avoid germs inadvertently contract their abdominal muscles, which in turn causes the pelvic floor muscles to contract. “You have to relax the pelvic floor muscle, let the bladder muscle do its job,” Dr. Berzuk says.

**Medications.** Most medications target storage problems. The most widely used medications for overactive bladder symptoms include a class of medications called **anticholinergics**. Brand names include:

- Ditropan®
- Detrol®
- VESicare®
- Enablex®
- Gelnique®
- Oxytrol®
- Pro-Banthine®
- Toviaz®
- Urispas®

Most of these are available in both the United States and Canada, although brand names may differ. These medications work by blocking the activity of a substance called **acetylcholine**, which is a neurotransmitter (nerve messenger); acetylcholine transmits messages to the brain but also stimulates contractions of muscles in the body. By blocking acetylcholine, these medications relax the detrusor muscle. In essence, says Dr. Murphy, by using these medications, “We stop the spasms, we increase capacity of the bladder and we give you that warning time—those few extra minutes that you need to get to the bathroom.”

A medication worked well for Muñiz. “The difference now is like night and day. The new prescription gives me the extra hour or sometimes two hours of holding it,” he says. “I’m more confident, sort of back to normal where I can go out, I can socialize. I won’t have to be embarrassed in front of my friends,” he adds.

Some of these medications come in pill form, while others are a patch or a topical gel. Though they all work in the same manner, you may need to try several before you find the one that is most effective for you. These medications do have side effects, which include dry mouth and constipation. They may also affect cognition. Since people with MS commonly experience constipation (see next section) and changes in their cognition, you and your healthcare provider will want to carefully consider this option.

A newer medication, called Myrbetriq® (mirabegron), aims to avoid these side effects. It comes from a different class of drugs, called **beta-agonists**. It relaxes the bladder muscle during the storage phase, reducing the number of contractions a person may experience. The most likely side effect is increased blood pressure. It can also make problems with emptying worse.

Recent research suggests that cannabis-derived oral or sprayed medications may also reduce spasticity associated with overactive bladder. However, further research is necessary before this can be recommended as a primary treatment.

For people whose nighttime bladder problems are not adequately controlled by these medications, a medication called desmopressin acetate may be prescribed. Desmopressin, which is a synthetic version of a naturally occurring hormone, temporarily reduces the amount of urine the kidneys produce.

Another treatment option is Botox® (onabotulinumtoxinA). While it's more widely known for eliminating wrinkles, this medication works by calming the nerve activity associated with the bladder muscle. This medication is provided as a series of injections into your detrusor muscle. The procedure takes only five or 10 minutes, and most people find that the results last for three to six months—and sometimes as long as nine months—before they need another set of injections. If you use Botox for other MS symptoms—such as facial pain, migraines or spasticity of the arms or legs—it's important that you tell your urologist. “The Botox needs to be injected on the same exact day by different providers,” says Dr. Murphy. “This has to do with antibody formation that occurs,” and could render later Botox treatments ineffective. Dr. Murphy says another potential problem with using Botox is that it might overly relax the bladder. In such cases, an individual might have to learn to perform intermittent self-catheterization (see next page) once or twice a day.

People who have emptying problems or combined dysfunction (problems with both storage and emptying) might be prescribed medications such as baclofen (Lioresal®) or tizanidine hydrochloride (Zanaflex®) to relax the sphincter. Other options include medications called **alpha-andrenergic blocking agents**, which promote the flow of urine through the sphincter. “These medications open that gate just a little wider so the bladder doesn't have to work so hard,” Dr. Murphy explains. Brand names include:

- Uroxatral® (United States only)
- Rapaflo®
- Cardura®
- Flomax® (Hytrin® in Canada).

**Catheterization.** People who experience post-void residual of more than 200 ml might be asked to consider using a catheter—a thin, hollow tube inserted into the urethra—one or more times a day to assist with emptying the bladder. “We can’t leave that urine behind,” Dr. Murphy says, or stones and infections could develop, further worsening bladder problems, and potentially affecting the kidneys and overall health. Known as **intermittent self-catheterization (ISC)**, this procedure can be done by men or women after a short instructional session with a nurse or other provider, and provides a clean, effective way of managing this residual. While the thought of using a catheter can be frightening initially, most people find that it’s easier and less uncomfortable than they imagined, and that it provides a great degree of freedom.

Michael Mohn attests to that. “Being a male, it’s a scary thing. The first thing you think is, ‘No way am I going to do that.’ But there are catheters out there that are very easy to use and cause very little discomfort when you put them in,” he says. “When you go out to a restaurant or something, you just need to make sure you can use a stall. There’s no embarrassment, and you never have to worry about having an accident.” Mohn says he’s been catheterizing for more than a year now. “It’s been a smooth process and it has changed my life tremendously. It really just made it so I could do normal things again.”

Dr. Murphy says that the procedure is usually easy to learn, and allows people who perform ISC to empty their bladders in the same amount of time as anyone else.

If an individual with MS is unable to perform ISC because of impaired dexterity or other issues, his or her partner may be able to do it. “A care partner needs to know that they can’t hurt the person with MS. They can’t perforate the bladder; they do not increase the risk for infection. And they’re really taking an active role in keeping their partner healthy,” Dr. Murphy says.

“Being a male, it’s a scary thing. The first thing you think is, ‘No way am I going to do that.’ But there are catheters out there that are very easy to use and cause very little discomfort when you put them in.”

If ISC is not successful, another option is an **indwelling catheter** (sometimes called a Foley catheter). It consists of a flexible rubber tube that remains in the bladder and drains urine into an external collection bag. It should not be left in long-term, though, because damage to the urethra is possible.

A more recent intervention is the inFlow™, an FDA-approved device designed to help with bladder drainage. The device, which is inserted into the urethra by a physician, helps to hold urine in place until a person is ready to void, and then helps pump urine out of the bladder. When an individual wishes to urinate, he or she sits on the toilet and activates the device with a handheld remote control. The device, which is an alternative to ISC, indwelling catheters and surgery, can be removed at any time. Each device lasts about a month and then must be replaced. The first one must be inserted by a physician; replacement devices can be inserted by any healthcare provider or patient who has received training. There are risks with this device, such as pain, bleeding and infection, so this, like all options, should be discussed in detail with a physician.

**Nerve stimulation.** A handful of techniques that stimulate certain nerves may also be effective in managing bladder symptoms. **Sacral nerve stimulation** (sometimes known as SNS, or by the brand name InterStim®) involves implanting a stopwatch-sized device, called a **neurostimulator**, in the upper buttocks. There, it works as a sort of pacemaker, emitting mild electrical pulses and helping the sacral nerves (the nerves that control the bladder) communicate more accurately with the brain. The implantation can be done in a couple of hours in an outpatient visit, and can be reversed at any time. One drawback is that people may not be able to have MRIs while the device is in place. It's been shown to improve urgency, frequency and retention problems in the general population, but its evidence for success in people with MS is limited.

Another type of nerve stimulation is **percutaneous tibial nerve stimulation (PTNS)**. In this procedure, a fine-needle electrode is placed on the inside of the ankle, or a small rubber electrode can be used on the skin, to stimulate the tibial nerve. PTNS sends an electrical pulse up to the sacral nerves to help them signal the bladder and pelvic floor muscles. People usually receive this treatment once or twice a week for 12 weeks. People who receive this treatment often report improvements in urinary frequency, urgency and incontinence.

**Surgery.** As a last resort, when neither lifestyle changes nor medications are effective, various surgical procedures might be considered. The simplest is called a **suprapubic cystostomy**, which involves making a small incision in the abdomen to insert a tube into the bladder. The tube drains the urine into an external collection bag. This can simplify personal hygiene for people who have less mobility or dexterity. Other surgical options are also available.

“I didn’t have to bring any extra supplies. I don’t have to drag things with me anymore. I can just be free.”

Surgery often brings about changes in body image, which require a period of adjustment. For people who have struggled with bladder symptoms without success, however, surgery can bring a newfound sense of relief and freedom. Many people find that they feel in control of their bodies in a way they haven’t experienced for quite some time.

Joan Molans Wood started having bladder issues about 10 years after being diagnosed with MS in 2000. She tried several options before discussing surgery with her urologist. She had a urinary diversion in 2014, and hasn’t looked back, she says, recalling a recent outing to see a Broadway play with friends. “Before my operation, I would have probably had to bring a knapsack with extra Depends and things like that. But I didn’t have to bring any extra supplies. I don’t have to drag things with me anymore. I can just be free.”

## SUMMARY

Bladder issues are complex and require thorough evaluation and persistence with a management plan. The important thing to remember is that there’s a solution to almost every bladder issue, and once you find it, you can get back to living your life—without embarrassment and without restrictions.

An abstract graphic design featuring two stylized hands reaching out from the top. The hands are rendered in shades of green and blue. The background is a complex composition of overlapping, semi-transparent shapes in various colors including blue, green, yellow, and purple. The overall aesthetic is modern and clean.

# **BOWEL HEALTH**

## INTRODUCTION

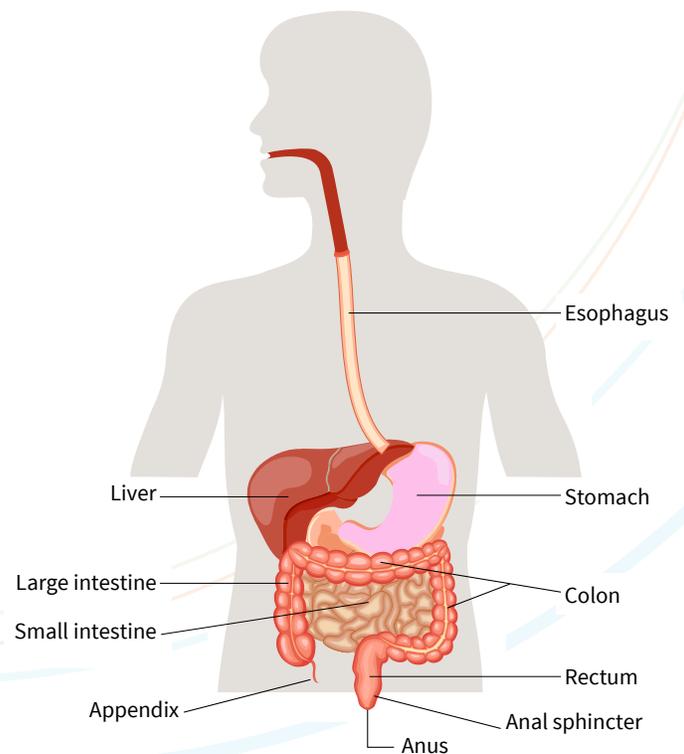
If you look at an anatomy book, you probably won't see an organ called the "bowel." The term is used as a kind of shorthand for the **small intestine** and **large intestine**. When we talk about bowel health in MS, however, we're primarily focused on the **colon**—the biggest segment of the large intestine—which is responsible for taking food that can't be used by the body and processing it into waste.

Before food ever reaches the colon, however, it's already been on a digestive journey. As soon as food enters the mouth, chewing and saliva begin breaking it down into a cohesive ball, or bolus. It's propelled through the esophagus to the stomach, then to the small intestine. During this process, stomach acids, digestive enzymes and bile break down the bolus even further, sending molecules of protein, carbohydrates, fats and other usable nutrients throughout the body via the bloodstream.

By the time any remaining material reaches the colon—a five-foot long tube—it has become mostly waste and water. The colon removes any excess fluid, so that when the waste arrives at the very end of the bowel—a segment called the sigmoid colon—very little water remains.

The final stop along the colon is the **rectum**. Once the stool arrives in the rectum, nerves in the rectal wall tell the brain that the rectum is full, and the **internal sphincter** opens automatically to allow the stool to enter the anal canal. The stool can then be voluntarily eliminated by opening the **external sphincter**. Most people have bowel movements anywhere from three times a day to three a week.

Or at least that's how it happens when everything is working perfectly. But for many people with MS, the process is less reliable—at least some of the time. In a 2014 survey of more than 3,500 people with MS in 73 countries (conducted by the MS International Federation, or MSIF), nearly 50 percent reported that bowel



*The digestive and "bowel" system*

problems are significant enough to interrupt their work, social activities and other aspects of day-to-day life at least some of the time. Typically, people with a higher degree of disability from MS experience more severe problems with bowel and bladder, according to studies, Dr. Newsome notes.

## **BOWEL PROBLEMS 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.

As with urinary problems, bowel problems can stem from MS damage in the brain and spinal cord, which causes miscommunication between the central nervous system and the intestines. Sometimes, other factors, such as medications, impaired mobility or diet are the culprits. It's common, too, for bowel problems to occur when an individual attempts to manage urinary symptoms by limiting his or her fluid intake. Without adequate fluids, the stool becomes dry and hard, leading to constipation.

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.

In addition, people with MS are more likely than the general population to develop autoimmune conditions of the bowel, says Dr. Mowry. These include celiac disease, Crohn's disease and other inflammatory conditions that alter the ease and speed with which contents move through the gut.

Bowel problems won't go away on their own, and may make other problems, such as spasticity and walking difficulties, worse. For these reasons, it's crucial to address bowel problems when they arise. Most people find that their quality of life improves dramatically once their bowel issues have been treated.

Read on for information about the bowel problems that people with MS are most likely to experience.

**Constipation.** This uncomfortable feeling of having a full rectum but being unable to have a bowel movement occurs in about a third of people with MS, according to the MSIF survey. Constipation is defined as having fewer than three bowel movements per week, or stools that are difficult to pass. Sometimes abdominal pain and bloating are present. Some people may also have difficulty emptying the rectum completely.

People who experience constipation regularly may begin to dread trips to the restroom, but putting them off can worsen the problem. And ongoing constipation is not a trivial matter, as it can lead to a number of complications. For example, the rectum may become chronically stretched, which sends messages to the spinal cord that interrupt bladder function. A full rectum can also put pressure on the bladder, creating urinary urgency. Constipation, like many other unpleasant stimuli or “triggers,” can also worsen other MS symptoms, including pain, numbness or tingling, and limb spasticity (muscle stiffness and/or spasms). It can also increase fatigue if an individual makes several unsuccessful trips to the bathroom, particularly if it involves transferring to a toilet from a wheelchair and back again. And if constipation is untreated, it can lead to bowel urgency (experienced by about a quarter of people with MS) and fecal incontinence.

Understanding why constipation happens is often the first step to overcoming it. Constipation occurs when the stool moves too slowly through the digestive tract, losing water along the way, and making it overly firm and difficult to pass. A number of MS-related factors can contribute to this slowing. These include:

- **Bladder problems.** “When people have difficulty emptying the bladder completely, it can put pressure on the bowels and change the dynamics of how the bowel is working, and thus lead to constipation,” says Dr. Mowry.
- **Limited mobility.** The gentle squeezing movements (called **peristalsis**) of the colon that help propel the stool through the digestive tract are greatly enhanced by physical activity. When a person with MS has fatigue or difficulty walking, these peristaltic waves don’t happen as efficiently, and the waste may back up in the colon, becoming dehydrated, dense and difficult to pass.
- **Nerve damage.** Slow passage of stool through the colon can also happen as a direct result of MS lesions that make communication between the bowel and brain ineffective.

- **Weak or spastic muscles.** If abdominal muscles are weak, the “bearing down” part of having a bowel movement can be difficult. If the muscles of the pelvic floor (including the external sphincter) are spastic, however, an individual may not be able to relax them sufficiently to allow elimination.
- **Inadequate fiber and fluid in the diet.** Dietary fiber—found in fruits, vegetables and whole grains—helps to “bulk up” the stool and keep it moving. A diet that relies heavily on processed foods may not include enough fiber. “My doctor’s telling me to eat more vegetables,” says Muñiz, who admits he’s not a fan of salads. “But one of the things that is really important to me is always staying fit. I realized that I only have one body, I have only one life, so I’ve got to just you know, take care of my body, because if I don’t, my body’s not going to take care of me.”

In addition, a diet without enough fluid may cause the stool to harden and be difficult to pass. “One mistake that people sometimes make is that they increase their fiber intake but they don’t balance that with their water intake, and it’s really critical that the two are matched,” says Dr. Berzuk.

- **Medications.** Some medications commonly used by people with MS may contribute to constipation. These include **anticholinergics** (ironically, often used to manage bladder dysfunction), calcium supplements (as well as antacids that contain calcium), some antidepressants, high blood pressure medications, **diuretics** (medications used to treat conditions such as chronic swelling, and which increase the amount of urine produced), sedatives and antipsychotic medications.
- **Habits.** When people with MS restrict their fluid intake to avoid urinary urgency or incontinence, their stools lack moisture, and will become difficult to pass. Another counter-effective habit is when people try to delay having a bowel movement because they’re involved in another activity, or because they don’t want to undergo the exertion of a trip to the restroom. In the short term, the rectum gets used to the sensation of being full and the urge to evacuate goes away, but delaying a bowel movement actually worsens the constipation in the long run.

**Diarrhea or involuntary bowel movements.** Diarrhea occurs much less commonly than constipation in people with MS. It occurs when the stool moves too quickly through the digestive tract and remains watery, reaching the rectum in a soft or liquid state. This may occur if MS causes an overactive bowel, with the bowel pushing the stool along too quickly, before it has had a chance to shed liquid. However, it is typically not accompanied by the feeling of stomach upset associated with bacterial or viral infections.

The following scenarios can also provoke loose stools or involuntary bowel movements.

- **Impaction**, a condition that occurs when hard stool becomes lodged in the rectum and cannot be eliminated. In such instances, the impacted stool blocks the bowel, causing any liquid stool to leak around the blockage. Impaction can lead to significant medical complications such as nausea and vomiting, tears in the colon wall or anus, and rectal bleeding, and must be treated immediately by your healthcare provider.
- Reduced sensation in the rectal area can enable the rectum to stretch more than usual, resulting in an unexpected, involuntary release of the external sphincter and its stool, which may be loose.

Ongoing diarrhea is not common in MS, and is more likely to be associated with infections, chronic dietary irritants or other gastrointestinal problems. Still, when it does occur, it can be extremely distressing. Fear of losing control of one's bowels can lead people to become anxious, depressed or both. They may be reluctant to leave their homes, and that social isolation in turn worsens their emotional symptoms.

And, says Dr. Murphy, bowel and bladder symptoms contribute to this isolation far more than physical limitations caused by MS. It's not the need for a cane or walker that keeps people at home, she says. "It's their fear of [lack of] bathroom access; it's their fear of wearing a diaper and having soaked through their clothes; it's the fear that they smell. They stop leaving the house because they're not sure they can get into a bathroom on time," she says. "That's not fair. And it's all fixable."

Angel Muñiz, who experienced bowel problems in addition to bladder problems, confirms this. "With my bowel movements, there were times when I was walking or driving with my friends, and I was literally going on myself. I had no intention of telling my friends—because they don't want to cross that line," he says. After a while,

they knew something was wrong, though, he says “because of the smell.” Finally, he says, “It was just the fact of me accepting it and getting help—that’s when things started turning around for me.”

Anyone who experiences more than occasional episodes of loose stools should see a physician for a thorough evaluation so that the cause and appropriate treatment plan can be determined.

## **DIAGNOSING BOWEL DYSFUNCTION**

Despite the fact that bowel problems are quite common in MS, the MSIF survey found that more than 40 percent of people did not discuss their bowel problems with their neurologist. It’s understandably an awkward topic to introduce but the rewards for doing so can be tremendous.

Most importantly, you’ll be able to avoid very serious medical complications or long-term effects of constipation and diarrhea. And not insignificantly, you’ll also be able to take steps to regain your freedom and peace of mind.

Your healthcare provider will probably begin his or her evaluation with a series of questions about your elimination habits to understand the nature and severity of the problem. You will be asked about:

- Elimination habits—to understand your usual bowel and bladder routine
- Medications—many can affect bowel function
- Fluid intake—reduced fluids can cause constipation
- Diet—many foods and beverages can affect bowel elimination
- Bladder health—bladder issues can provoke bowel changes
- Level of physical activity—reduced mobility may lead to constipation
- Recent illnesses—may affect your usual bowel patterns
- Recent travel—exposure to different foods or food contaminants can cause bowel changes

The information from this series of questions usually provides enough diagnostic data to begin treatment. In some instances, your provider may need more information to determine what is causing your symptoms, in which case you would be referred to a gastroenterologist for additional testing. These tests could include,

- A clinical exam that gauges the sensitivity of your pelvic floor, as well as your ability to voluntarily initiate a bowel movement
- **Colonoscopy**—a test in which a thin, flexible tube with a light on the end is inserted into the rectum to view the lining of colon. This is recommended for anyone over age 50, with or without MS, to screen for polyps.
- **Abdominal radiography**—a series of X-rays that measure the amount of time it takes your stool to move through the bowel.
- **Anorectal manometry**—an assessment of the amount of pressure present on the anal sphincter, both at rest and while straining, as well as an assessment of how much sensation you have in the rectum. (This study can be useful in cases of incontinence or urgency because reduced rectal sensation can lead to stools leaking out before the sphincter has received a signal to contract.)
- **Defecography** (also known as **dynamic proctography**)—a video recording of the anus, rectum and pelvic floor musculature. This imaging is done while the person is at rest, while coughing and while trying to pass barium paste (which shows up on the video) from the rectum. This allows your provider to see how efficiently your anorectal muscles work through various stages of defecation, and determine whether there may be some kind of obstruction.

Based on the results of these tests, your healthcare provider will be able to recommend the best approach to treating your symptoms—so you can get back to the important things in your life.

## ESTABLISHING GOOD BOWEL HABITS

Dietary and lifestyle changes are the first line of treatment for managing bowel disturbances and for preventing them in the first place. “You start with the thing that is easiest for you and the thing that is probably most natural for your body,” Kennedy says. “Be careful,” she adds, “and don’t ever do them all at once.” Many healthcare providers urge people with bowel difficulties to start with **the three F’s: fiber, fluid and fitness**.

Here’s what you need to know about each.

**Fiber.** Fiber is the material in plant-based foods that holds water and is resistant to digestion. The water held in fiber helps keep the stool soft, and the fiber itself adds bulk to the stool to keep it moving. This helps prevent constipation or, worse, impaction. Somewhat surprisingly, fiber can also help prevent diarrhea, since it can absorb extra fluid.

Most experts recommend consuming 25 to 35 grams of fiber a day—though you may have to build up slowly to avoid gas, bloating and diarrhea. And the right amount may differ among individuals. “More importantly to me, as a clinician, is what the stool looks like,” says Dr. Berzuk, noting that whether it’s too loose or too firm will provide significant information.

Raw fruits, vegetables and whole grains are the best sources of fiber. A cup of green peas has about 9 grams of fiber, while an average apple (with skin) has about 4 grams. Dried fruits, such as prunes or apricots, can also be useful, with one cup of dried apricots providing 9.5 grams of fiber. You can find the fiber content of fresh fruits and vegetables on the U.S. Department of Agriculture website [www.usda.gov](http://www.usda.gov) and searching “foods list”. If you get your fiber through packaged foods such as cereals and breads, the amount per serving will be listed on the Nutrition Facts panel.

Sometimes it’s difficult to get enough fiber through diet alone. In such cases, your provider may recommend that you try a fiber supplement (sometimes called a “bulk-forming supplement”), such as Benefiber<sup>®</sup>, Citrucel<sup>®</sup>, or Metamucil<sup>®</sup>. These should be taken with one or two glasses of clear fluid (water, apple juice, broth or tea).

**Fluids.** It's difficult to overstate the importance of drinking enough each day. Many people with MS restrict fluids to avoid bladder urgency; if this is true for you, your healthcare provider will likely address your urinary issue first, and then treat your bowel symptoms once that is under control.

Without enough liquids, the digestive system will become constipated. That can lead to impaction, possibly with loose stool leaking out around it. Constipation can also worsen urinary urgency, since a full bowel pushes on the bladder. The best way to prevent this kind of domino effect is to time your fluid intake. Try to finish drinking at least two hours before any activity that you don't want to have interrupted by a bathroom break.

Aim to drink six to eight 8-ounce glasses of water or other liquids each day. Juices, milk and other beverages count—as long as they're not caffeinated, carbonated, alcoholic or acidic (those types of beverages can irritate the bladder and make co-existing bladder and bowel problems worse).

**Fitness.** Staying active helps keep the intestinal contents moving. In 2013, the Canadian Society for Exercise Physiology (CSEP), in partnership with the MS Society of Canada, released the Canadian Physical Activity Guidelines for Adults with MS. The guidelines recommend that adults with MS with mild or moderate disability strive for at least 30 minutes of aerobic activity two days a week, and strength training of major muscle groups two times each week. Aerobic activity might include walking, arm cycling or using an elliptical trainer. Strength training could involve elastic resistance bands, free weights or weight machines. Aerobic and strength conditioning can be done on the same days or can be alternated. People who have less mobility or strength can still increase their activity, says Kennedy. "Even if a person can move around in their chair, if they can make some transfers, if they can walk just a few steps around their living room, it all counts."

While those three factors will go a long way toward improving bowel health, there's still more you can do.

**Schedule a sit-down.** If you can establish a regular time each day for a bowel movement, you will be able to "train" your system to empty comfortably. At first, says Kennedy, "You may not go at all or you may have an accident. There will be mistakes on the road to learning how to train your body. After a while, though, it will begin to work."

For many people, the best time to do this is 20 to 30 minutes after eating or drinking something warm—that’s when the emptying reflex is strongest. Most people find that it’s particularly strong after breakfast. “Sometimes people find that drinking lemon water or warm water in the morning might be a real beneficial way to get things moving for them ... or with that cup of coffee, perhaps,” says Kennedy.

Even if you don’t feel the urge to go, adhere to your schedule, and allow about 10 minutes to initiate and complete the bowel movement. If it doesn’t happen easily, you may find that rocking gently back and forth on the toilet can help; or sometimes, placing your feet on a stool helps create an easier angle for stool movement.

A regular schedule is just as important for incontinence as for constipation, if not more so. When the bowel becomes accustomed to emptying at the same time each day, accidents are less likely to occur.

**Relax.** It’s easy to become anxious over bowel irregularities. But—whether related to toileting troubles or something else—tension can make matters worse. “Don’t ever strain,” Dr Berzuk advises. “Don’t hold your breath and push. You’re only injuring the muscle further.” Instead, she says, blow your breath out. Try deep breathing, visualization or any other relaxation techniques that work for you. And if your emotions become a source of concern, visit your healthcare provider. Depression can actually cause constipation, so it’s important to treat that, too.

**Journal.** Keep a food diary so you can identify patterns between your diet and your bowel habits. You may discover that certain types of food trigger digestive distress.

**Expect the unexpected.** It’s a good idea to keep a change of clothing and disposable wipes on hand for accidents.

A regular schedule is just as important for incontinence as for constipation, if not more so.

## TREATMENT OPTIONS FOR BOWEL DYSFUNCTION

Some people may find that lifestyle adjustments don't fully solve their bowel issues. In such instances, their healthcare providers may suggest certain over-the-counter (OTC) or prescription medications. Here's a look at some of the most common treatments for constipation. As with any medications and supplements you may take, make sure you speak with your healthcare provider. And, cautions Kennedy, "Don't ever do them all at once." Instead, keep a log so you have a record of which treatment you tried, for how long, and what level of success it brought you.

**Stool softeners.** These pills draw water and fat into the stool to soften it and enable it to pass more easily through the digestive tract. Some common OTC brands are Colace<sup>®</sup> and Surfak<sup>®</sup> (docusate). These can reduce the absorption of fat-soluble vitamins (such as vitamins A, D, E and K), so be sure to discuss any concerns about this with your provider.

**Laxatives.** While these oral medications work in a similar fashion to stool softeners, they have a bit more potency. Some types of laxatives, known as **osmotics**, simply pull water into the intestine to soften the stool and help it move. Within this category are liquid sugar concentrates, such as lactulose. In the United States, these liquid sugars require a prescription, since they may be dangerous for diabetics. They usually produce a bowel movement relatively quickly—often within an hour or so, though it can take up to a day or two. MiraLAX (polyethylene glycol) works in a similar fashion but is available OTC, and generally produces a bowel movement within 12-72 hours.

Another type of osmotic laxative, known as a **saline laxative**, pulls water into the intestine and also increases pressure within the intestine to help propel the stool. Examples of this include Milk of Magnesia<sup>®</sup> and Epsom salts; they generally produce a bowel movement within 30 minutes to six hours.

Another category, called a **stimulant laxative**, works by prodding the colon's wave-like movements with a chemical irritant; these include Dulcolax<sup>®</sup> (bisacodyl), Ex-Lax<sup>®</sup> and Senokot<sup>®</sup> (sennosides) pills.

Finally, a **lubricant laxative**, such as mineral oil, can help retain moisture in the stool by coating it (and the bowel) with a waterproof film.

The downside to laxatives is that they may produce an urgent, loose bowel movement, or uncomfortable abdominal symptoms such as gas, bloating and cramps.

Laxatives are recommended for short-term use only because they can become habit forming—meaning that the bowel will not move without their use. It is important to talk to your provider about the use of laxatives.

**Suppositories.** If stool softeners and laxatives don't do the trick, the next step might be to try a glycerin suppository, which you or your spouse or caregiver insert along your rectal wall. This generally produces a bowel movement within 20 to 30 minutes.

Dulcolax is also available as a suppository, but it contains a laxative medication and can be habit-forming.

**Enemas.** This involves injecting fluid into the bowel via the anus to stimulate a bowel movement. Common brands include Therevac<sup>®</sup>, Fleet<sup>®</sup> and Colace. Enemas should be used sparingly because the body may start to depend on them, but your healthcare provider may recommend using them in combination with stool softeners, laxatives or other therapies.

**Prescription medications.** Newer medications, such as Amitzia<sup>®</sup> (lubiprostone) and Linzess<sup>®</sup> (linaclotide)—the latter is known as Constella<sup>®</sup> in Canada—can be useful for chronic constipation. They work in a similar fashion to OTC osmotics. Side effects can include nausea, diarrhea and abdominal pain, but these tend to be infrequent.

Beyond medications, various therapies may also prove helpful for both constipation and diarrhea. These include the following:

**Manual stimulation.** Sometimes, gently massaging the abdomen in a clockwise direction can encourage a bowel movement. Another option is for you or a caregiver to insert a finger (covered with a plastic glove that has been coated with a lubricant, such as K-Y Jelly) into the rectum and rotate it gently. “That stimulates the nervous system so it [gets the message], ‘I’m supposed to be doing something here,’ and it will cause the stool to begin the movement to the outside [of the body],” Kennedy explains.

**Pelvic floor therapy.** A therapist with special training guides you in performing exercises that strengthen the muscles that support the bladder, bowel and other parts of the pelvic floor. Electronic sensors monitor and provide visual feedback on how well you're contracting and relaxing specific muscles. (See additional description in bladder section.) This treatment can be used for both constipation and incontinence. There are no known side effects, and it's usually covered by insurance.

**Sacral nerve stimulation (SNS).** This treatment, which is also used to improve bladder function, can help improve incontinence but not constipation. SNS involves implanting a stopwatch-sized device, called a **neurostimulator**, in the upper buttocks. There, it works as a sort of pacemaker for the digestive tract. Mild electrical impulses remind the sphincter and pelvic floor muscles to contract, improving communication between those regions and the brain. Mild side effects might include pain and soreness at the incision site (where the neurostimulator was implanted) for a couple of weeks, as well as a slight tingling, tapping or pulling sensation. In addition, people may not be able to have MRIs while the device is in place. Complications are rare but could include infection or pain, as well as technical problems with the SNS device.

“In time, if these treatments aren’t working, or [the bowel problem is] worsening, it might be time to see a neuro-gastroenterologist,” Kennedy says. “People with MS ... in helping to manage their own disease, need to be prepared to talk with their physician about what’s going on with their bowels.”

## CONCLUSION

When bladders and bowels are healthy, they operate mostly behind-the-scenes, keeping things running smoothly, and commanding our attention only a few times a day. In that way, they’re sort of like bus and train schedules; when they’re working, a city hums along nicely, but when they’re not, everything seems to back up, and people find themselves in unexpected places at unexpected times.

Unlike in a massive metropolis, however, there’s a lot that’s under our control when it comes to improving and maintaining bladder and bowel health. It only requires starting a frank conversation with your healthcare provider, and the payoff—in terms of your overall health and freedom to live the life you want—can be enormous.

An abstract graphic design featuring two stylized hands reaching out from the top. The hands are rendered in shades of green and blue. The background is a complex composition of overlapping, semi-transparent geometric shapes in various colors including blue, green, yellow, and purple. The word "RESOURCES" is centered in the middle of the image in a bold, white, sans-serif font.

# RESOURCES

# NATIONAL MS SOCIETY RESOURCES

The National MS Society has an extensive library of resources about MS, including publications about treatment options, symptom management and living well with MS.

The Society's MS Navigators also offer assistance in answering questions about living with MS. These highly skilled professionals can help you connect to resources in your community, access optimal healthcare, meet workplace challenges, understand health insurance, plan for the future and much more. Whether you are a person living with MS, a family member or someone who cares about a person with MS, you can call an MS Navigator at 1-800-344-4867 during business hours, Monday through Friday. You can also email us at [contactusnmss@nmss.org](mailto:contactusnmss@nmss.org) or find us on Facebook at [facebook.com/NavigatorMS](https://www.facebook.com/NavigatorMS).

This program's companion video is available by calling 1-800-344-4867, and online at [nationalMSSociety.org/videos](https://www.nationalMSSociety.org/videos).

The following articles and brochures, available online or by calling 1-800-344-4867, may prove especially helpful in learning more about how bladder and bowel health interact with a person's experience of MS.

## Bladder

### Urinary Dysfunction & MS:

#### [Managing Specific Issues — nationalMSSociety.org/all-brochures](https://www.nationalMSSociety.org/all-brochures)

This booklet provides an explanation of the most common types of MS-related urinary problems and treatments for them. It includes detailed descriptions of diagnostic testing, management strategies and commonly prescribed drugs.

#### [Bladder Problems — nationalMSSociety.org/bladder](https://www.nationalMSSociety.org/bladder)

This page provides an overview and links to more in-depth discussions and worksheets about bladder health in people with MS. It provides information about diagnosis and treatment options, as well as how bladder problems may affect other aspects of MS.

#### [Yes, You Can Regain Bladder Control — MomentumMagazineOnline.com](https://www.MomentumMagazineOnline.com)

Bladder problems affect most people with MS, but you don't have to just live with them. This article describes the latest strategies for improving bladder function and minimizing accidents.

## Bowel

### **Bowel Problems: The Basic Facts** — [nationalMSSociety.org/all-brochures](http://nationalMSSociety.org/all-brochures)

This booklet describes the basic anatomy of the digestive system, including the bowel, and its normal functioning. It explains the most common types of MS-related bowel problems and multiple approaches to managing them.

### **Bowel Problems** — [nationalMSSociety.org/bowel](http://nationalMSSociety.org/bowel)

This page provides an overview and links to more in-depth discussions and videos about bowel problems in people with MS.

### **Bowel issues? Help is here!** — [MomentumMagazineOnline.com](http://MomentumMagazineOnline.com)

Bowel problems are common—and among the most emotionally upsetting—symptoms of MS. This article explains what might happen and why, and how these problems are being treated successfully.

## MS SOCIETY OF CANADA RESOURCES

### **Bladder Dysfunction in MS** — [mssociety.ca/en/pdf/bladder-dysfunction.pdf](http://mssociety.ca/en/pdf/bladder-dysfunction.pdf)

This information sheet discusses the common and upsetting symptom of bladder dysfunction.

### **Urinary Dysfunction and MS: A Guide for**

### **People with MS** — [mssociety.ca/en/pdf/2012-Urinary-Dysfunction-EN.pdf](http://mssociety.ca/en/pdf/2012-Urinary-Dysfunction-EN.pdf)

This booklet is a comprehensive guide to MS-related urinary problems. It includes detailed descriptions of diagnostic testing, management strategies and commonly prescribed medications.

### **Understanding Bowel Dysfunction** — [mssociety.ca/en/pdf/bowel.pdf](http://mssociety.ca/en/pdf/bowel.pdf)

This booklet describes the impact of MS on bowel functioning and also suggests good bowel habits.

## ADDITIONAL RESOURCES

The following publications and organizations may be able to help you access the providers and care you need.

**MS In Focus: Bladder & Bowel, July 2014** — <http://ntl.ms/MSIFJul14>

**Urinary Incontinence Fact Sheet for Women** — <http://ntl.ms/womensurinary>

**Urinary Incontinence Fact Sheet for Men** — <http://ntl.ms/mensurinary>

**National Association for Continence** — [nafc.org](http://nafc.org)

A consumer advocacy and educational group aimed at understanding and managing bladder and bowel dysfunction. NAFC provides referrals to healthcare professionals specializing in the diagnosis and treatment of these issues, including urologists, gynecologists, physical therapists and nurse practitioners. It also offers an absorbent product program; for information, call 800-252-8887.

**Urology Care Foundation** — [urologyhealth.org](http://urologyhealth.org)

Previously known as the American Urological Associations' Foundation, this group works to advance urologic research and education to improve the lives of people living with urinary dysfunction. The UCF's website has a search tool to locate any of more than 19,000 urologists.

The background is a vibrant, abstract composition of overlapping geometric shapes in various shades of blue, green, yellow, and purple. In the upper portion, a stylized figure is depicted with arms raised, rendered in shades of green and blue. The overall aesthetic is modern and dynamic.

# GLOSSARY

**Acetylcholine.** A neurotransmitter, or substance that carries messages to the brain and also stimulates contractions of muscles in the body. Can be responsible for overactivity of bladder muscle.

**Alpha-andrenergic blocking agents.** Medications that promote the flow of urine.

**Anticholinergics.** Medications used for overactive bladder. They work by blocking acetylcholine.

**Beta-agonists.** Medications that relax an overactive bladder muscle during the storage phase, reducing the number of contractions a person may experience.

**Bladder.** A hollow, muscular pouch in the pelvic cavity that stores urine.

**Catheter.** A thin, hollow tube inserted into the urethra to empty the bladder.

**Colon.** The biggest segment of the large intestine. Responsible for taking food that can't be used by the body and processing it into waste.

**Colonoscopy.** A test in which a thin, flexible tube with a light on the end is inserted into the rectum to view the lining of colon.

**Combined dysfunction.** A urinary storage problem and an emptying problem that happen at the same time.

**Constipation.** A condition in which a person has fewer than three bowel movements per week, or stools that are difficult to pass.

**Demyelination.** Damage to the myelin sheath that insulates nerve fibers.

**Detrusor.** The muscle in the bladder that contracts to expel urine and expands to retain it.

**Diarrhea.** A condition in which a person has loose, watery stools. Often caused by illness or gastric irritants.

**Diuretics.** Medications that are used to treat conditions such as chronic swelling, and that increase the amount of urine produced.

**Emptying problems.** When the demyelinated nerves in the spinal cord are unable to 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.

**Enema.** A treatment in which fluid is injected into the bowel via the anus to stimulate a bowel movement.

**Fiber.** The material in plant-based foods that holds water and is resistant to digestion. The water held in fiber helps keep the stool soft, and the fiber itself adds bulk to the stool to keep it moving.

**Frequency.** The need to urinate often, even if urination occurred very recently.

**Gastroenterologist.** A physician who specializes in disorders of the digestive tract.

**Impaction.** A condition that occurs when hard stool becomes lodged in the rectum and cannot be eliminated.

**Incontinence.** The inability to control when and where to urinate or defecate.

**Indwelling catheter.** A flexible rubber tube that remains in the bladder and drains urine into an external collection bag. Sometimes called a Foley catheter.

**Intermittent self-catheterization (ISC).** A process in which an individual inserts a thin, hollow tube into his or her urethra one or more times a day to assist with emptying the bladder.

**Kegels.** Pelvic floor exercises in which an individual alternately contracts and relaxes the muscles that stop urine in midstream. These exercises help to strengthen and coordinate the pelvic muscles.

**Kidneys.** The two organs in the abdominal cavity that remove impurities and water from the blood, resulting in urine.

**Large intestine.** The part of the digestive system responsible for absorbing excess water from indigestible food (waste). Includes the colon and the rectum.

**Laxatives.** Medications, often available over the counter, that help propel the stool when an individual is constipated. There are several types of laxatives, including lubricant, osmotic, saline and stimulant.

**Myelin.** The sheath that insulates nerves, and is damaged by MS.

**Neurostimulator.** A stopwatch-sized device that emits mild electrical pulses to help the nerves that control the bladder and bowel communicate more accurately with the brain.

**Pelvic floor rehabilitation.** A type of treatment involving biofeedback that allows an individual and his or her therapist to see how well the pelvic muscles are being used and coordinated, and then work to improve them.

**Percutaneous tibial nerve stimulation (PTNS).** A procedure in which a fine-needle electrode, or a small rubber electrode on the skin, is placed on the inside of the ankle to stimulate the tibial nerve. PTNS then sends an electrical pulse up to the sacral nerves to help them signal the bladder and pelvic floor muscles. This procedure is repeated for several weeks to improve urinary urgency and frequency.

**Peristalsis.** The gentle squeezing movements of the colon that help propel stool through the digestive tract.

**Post-void residual (PVR).** When some urine is retained in the bladder even after urination (voiding).

**Pseudoexacerbation.** A condition in which a person's MS symptoms temporarily worsen as the result of an infection or other temporary condition. Not the same as a true exacerbation (or flare up) of MS.

**Rectum.** The final section of the large intestine.

**Sacral nerve stimulation.** A procedure used for both bladder and bowel health that involves implanting a neurostimulator in the upper buttocks. There, it works as a sort of pacemaker for the digestive tract. Mild electrical impulses remind the sphincter and pelvic floor muscles to contract, improving communication between those regions and the brain.

**Small intestine.** A part of the digestive system responsible for breaking food down into usable nutrients.

**Sphincter.** In the lower urinary tract, the **internal** and **external sphincters** are circular bands of muscle fibers located between the bladder and urethra. The internal sphincter is controlled involuntarily and helps to keep the urethra closed, while the external sphincter can be relaxed and tightened consciously. In the rectum, the internal sphincter opens automatically to allow the stool to enter the anal canal. The stool can then be voluntarily eliminated by opening the external sphincter.

**Stool softener.** Pills that draw water and fat into the stool to soften it and enable it to pass more easily through the digestive tract.

**Storage problems.** When an overactive detrusor muscle begins to contract as soon as a small amount of urine has accumulated, preventing a person's ability to store urine in the bladder effectively.

**Suprapubic cystostomy.** A type of surgery in which a small incision is made in the abdomen and a tube is inserted into the bladder. The tube drains the urine into an external collection bag.

**Suppository.** A type of medication (generally sold over the counter) that you or your care partner insert along your rectal wall. This generally produces a bowel movement within 20 to 30 minutes.

**Ureters.** Thin tubes—one leading from each kidney—that carry urine to the bladder.

**Urethra.** The tube that carries the urine from the bladder to the outside of the body.

**Urgency.** The sudden and intense urge to urinate immediately.

**Urinary diversion procedure.** A procedure by which the bladder is removed and a new conduit for urine is created via a segment of small intestine. Not a procedure that is commonly used.

**Urinary tract infection (UTI).** An infection in any part of the urinary system, including the kidneys, bladder or urethra. Untreated UTIs can lead to serious health complications.

**Urodynamics.** An evaluation of bladder function in real time, which can show how well a person's pelvic floor and bladder muscles work together.







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