

# Yes, you can regain bladder control

With so many treatment strategies available, there's a solution for almost everyone.

by Aviva Patz

Let's talk about pee. Seriously. You may think hitting the bathroom three times during the night, leaking a few drops here or there or feeling unable to go are things you just have to cover up and live with as best you can; if so, think again. Bladder problems affect 75 to 90 percent of people with multiple sclerosis, according to a July 2014 in-depth report in **MS in Focus**, published by the Multiple Sclerosis International Foundation (MSIF). "Patients need to understand that bladder issues are a symptom of their disease process and not something they should be embarrassed or ashamed about," says Dr. Marlene Murphy Setzko, a urologist and director of Urologic Services at the Mandell Center for Comprehensive MS Care in Hartford, Connecticut.

That said, it's understandable that these symptoms are extremely distressing. "One of the first things we learn as infants is how to control our bladder, so losing that ability can dash our self-esteem," says psychologist Rosalind Kalb, PhD, vice president of Clinical Care at the National MS Society. "It's hard to present yourself to the world when you're worried you're going to wet your pants."

Perhaps even worse, bladder problems can be debilitating, potentially leading to depression, social isolation, poorer performance at work, skin breakdown, infections and a greater likelihood of needing to move to an extended care facility.

In spite of the discomfort and disability this issue can cause, many people hesitate to seek help. They shouldn't.

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“Seeing and reading all the ads for bladder issues made me think that it was normal,” says Claire P., of Annapolis, Maryland, who was diagnosed with MS in 2001. In fact, while it’s not “normal,” it **is** common.

In MSIF’s July 2014 survey of more than 3,500 people living with MS in 73 countries, more than a third of those who hadn’t been tested for urinary problems also had not brought up the topic with their neurologist. A quarter said they preferred to manage the symptoms on their own, and another quarter who had not been treated said their neurologist thought testing was unnecessary.

Clearly, bladder issues in MS are under-recognized, underdiagnosed and undertreated. “Patients are often shocked to learn that urologists with an interest in MS actually exist, and that essentially, there is a solution to every bladder problem—and that solution doesn’t have to include adult diapers!” Dr. Murphy says.

Read on to learn what bladder difficulties in MS look like and why they happen, plus the newest treatments and real-life coping mechanisms.

“Taking the steps that will help you get this essential bodily function under control is critically important,” Dr. Kalb adds. “Talking with your doctor or nurse is the first step to finding the right solutions.”

### The what and why of symptoms

The bladder has two main functions—to store or hold urine, and to empty effectively. But in people with MS, this often doesn’t go as planned. Why? Chalk it up to miscommunication. We know that in MS, myelin—the fatty substance that surrounds and protects nerve fibers—is damaged. When myelin is compromised, signals traveling along nerve fibers to and from the brain and spinal cord get garbled. “It’s like the game ‘telephone,’” Dr. Murphy says. “By the time the word gets to your bladder, it doesn’t know what the word is or what to do.”

When it comes to storage problems, the most common symptoms, collectively called “overactive bladder” (OAB), include:

■ **Urgency and/or frequency**—the sudden and intense urge to urinate. This may occur even if you just went 10 minutes ago. These symptoms can come from involuntary contractions of the bladder that your willpower is unable to override. They may be triggered by touching

or hearing running water, or by passing a bathroom.

■ **Incontinence**—not being able to control where and when you go. It may involve emptying the whole bladder. You may not feel the sensation of a full bladder (until it’s too late) because nerves governing storage lose sensitivity. Compounding the problem is worsening mobility, a common symptom in MS, which can make it challenging to get to the bathroom on time.

■ **Nocturia**—related to urgency and frequency, this involves waking up at night to go.

“Symptoms of overactive bladder become increasingly common with the duration and progression of MS,” says Dr. Andrew M. Shapiro, chief of urology at the University of Maryland Rehabilitation and Orthopaedic Institute.

People with MS can also have problems with emptying. So although the bladder gets full, key signals—to hit the bathroom and to relax the sphincter (so urine can be released)—don’t arrive in a timely way. The bladder continues to fill, like a water balloon, until it’s enlarged and overly relaxed, triggering urgency and incontinence as well as these additional symptoms:

■ **Hesitancy**—a delay in the ability to initiate urination even though the urge is there. The problem here may be jammed signals: In normal bladder function, the sphincter relaxes and opens when the bladder contracts, but in MS, the two can contract at the same time, causing difficulty peeing; a weak and intermittent trickle; or incomplete voiding, where the bladder doesn’t completely empty. In some cases, people can’t void at all.

■ **Dribbling**—similar to incontinence but usually involves involuntary leakage of just a few drops of urine. If the bladder doesn’t empty properly and retains some urine, it can lead to complications such as repeated urinary tract infections (UTIs) or even kidney damage.

### First line of treatment

Self-management strategies were shown, in a 2009 study in the **International Journal of Clinical Practice**, to significantly improve daily bladder and bowel symptoms. “These strategies are important because they give people back a sense of control,” Dr. Kalb says. They include:

Learning ways to manipulate the pelvic floor can help control urgency and leakage. Learn more on p. 32.

- **Drinking enough.** Some people cut back their fluid intake to minimize urgency and prevent accidents, but dehydration can actually worsen symptoms—the urine can become so concentrated that it irritates the bladder, triggering incontinence. Instead, make sure you’re drinking enough to keep your urine light yellow. It will flush waste, bacteria and mineral deposits to help you avoid infection. Bonus: It will also help keep stool soft to avoid constipation. That said, you might want to space it out, drinking no more than 4 to 6 ounces per hour.
- **Drinking strategically.** Exceptions to the rule above: Restrict fluids about two hours before an activity where there will be no bathroom breaks and before bedtime, to avoid nighttime waking.
- **Getting regular.** Schedule bathroom breaks just ahead of when you usually feel urgency, or every two

- hours. You’ll train your bladder, avoid overfilling it and reduce the chances of an accident.
- **Strength training.** Pelvic floor exercises (Kegels) get you contracting and relaxing the muscles that support the urethra, bladder, uterus (for women) and rectum to help you manage incontinence. Yes, men can do Kegels, too. For instructions, visit [mayoclinic.org](http://mayoclinic.org) and search for “men’s Kegels.”
- **Avoiding irritants.** Limit caffeinated beverages (coffee, tea and soda), alcohol and artificial sweeteners, which can irritate the bladder and worsen storage problems.
- **Eliminating residual urine.** If your doctor finds that you’re retaining a certain amount of urine after going to the bathroom, you may be advised to use a catheter three to four times a day to ensure complete emptying.



Learn even more in the Society’s telelearning program on bladder & bowel issues in MS on March 17 or 19. Visit [nationalMSSociety.org/telelearning](http://nationalMSSociety.org/telelearning) or call 1-800-344-4867 to register.



For help finding a urologist with expertise in MS-related bladder management issues, call an MS Navigator at 1-800-344-4867.





### Newest treatments

There's no one-size-fits-all therapy. "Every patient has unique issues and a unique set of treatment goals," Dr. Shapiro says. Your doctor can help tailor a treatment plan to your specific concerns—such as an overactive bladder or difficulty emptying (or some combination thereof)—as well as the way your body responds to the various treatment options. So the first step is a thorough exam and testing to get to the root of the problem.

"Do not be embarrassed," Claire advises. "Healthcare professionals cannot help you unless you tell them everything. The right doctors with the right information can improve your life dramatically!"

Most likely, your doctor will start with a simple urinalysis to test for a possible UTI, which is common in people with MS. If it's positive, you'll likely get antibiotics. If it's negative, the next step is urodynamics, an evaluation of your bladder function in real-time that allows doctors to observe how your pelvic floor and bladder work together (or not so much, as the case may be). Your doctor may also use a catheter to check how much urine remains in your bladder, which could signal problems with emptying. Your doctor may also check your kidneys.

Whatever testing reveals, many promising treatment options are now available. "Up until five years ago, I had only medication and surgery options; there were no intermediate steps," Dr. Murphy says. "Now I have lots of tools in my toolbox that help people avoid major reconstructive surgery and give them back their quality of life."

■ **Medication.** Drugs known as anticholinergics (such as Ditropan, Detrol, Vesicare, Enablex, Gelnique, Oxytrol and Toviaz) suppress involuntary bladder contractions to help with urgency, frequency and urgency-related leakage. Anticholinergics are available as a pill, a patch or a topical gel. Side effects can include cognitive impairment, dry eye, dry mouth and constipation, leading some 80 percent of people to quit the medications.



### Lifestyle coping strategies

Use these expert tips, including a few from people with MS who found ways to make their bladder issues easier to manage day to day.

**PACK A SPARE.** Stock your car and office with emergency packs. Include clean undies, wipes, an absorbent pad, a pair of pants and a large zippable bag for dirty clothes.

**STAY PROTECTED.** Wear an absorbent pad in case of accidents. Men can try an external collection unit (such as a Texas catheter) for discreet drainage.

**SPOT THE BATHROOMS.** A handful of apps—including Sit or Squat, Where to Wee, Toilet Finder and more—can point you toward the nearest toilet. "I knew where every bathroom was for every store that I shopped in, because when I had to go, I had to go!" Claire P., of Annapolis, Maryland, says. "When you do have an accident, your day is ruined, both mentally and physically."

**GIVE YOURSELF TIME.** To prevent a self-flushing toilet in a public restroom from flushing repeatedly while you're using it, cover the electronic eye with a sheet of wet toilet paper.

**KEEP IT LOOSE.** Skip the belt and steer clear of pants with multiple buttons, drawstrings and other complicated closures that could get in the way. Also avoid constricting clothes that could amp up feelings of urgency.

**TRY CAMOUFLAGE.** To conceal minor accidents that don't require a wardrobe change, choose dark-colored or patterned clothing and wear long, lightweight jackets or cardigans whenever possible.

**DRESS YOUR BED.** If nighttime wetting is an issue, add a waterproof liner beneath your sheets to make clean-ups quicker. You might also consider putting a portable commode near the bed for easy access—and keep a flashlight at bedside so you can find your way!

**RALLY SUPPORT.** If you're comfortable sharing your issue with family and close friends, they can be a source of support—and even comic relief—at times when you need cover for a quick exit or to borrow a fresh pair of underwear. "Far from driving a wedge between you, sharing this intimate information may bring you closer," Rosalind Kalb, PhD, of the National MS Society says, "not to mention making it easier to manage your symptoms."



A newer treatment called Myrbetriq, which is a type of medication called a beta-agonist, aims to avoid the side effects. Approved by the FDA in 2012, it works by reducing muscle contractions, which promotes greater retention in the bladder to reduce urgency, frequency and incontinence. A bump in blood pressure is a possible side effect. Most medications are covered by insurance, but, as Dr. Murphy notes, out-of-pocket expenses can reach \$100 a month.

Expect some trial and error when it comes to finding the right medications. Claire notes that she started out on one drug and had to switch a few years later when the first one lost its effectiveness.

■ **Pelvic floor rehabilitation.** Though people can do Kegel exercises on their own, working with a specialized therapist to learn other ways to manipulate the muscles of the pelvic floor can help control urgency and leakage. Using a pelvic probe fitted with sensors, people try to contract and relax their pelvic floor muscles while looking at the results—a rising and falling bar graph—on a computer screen. “It shows how well you’re recruiting different muscles,” says Connecticut-based pelvic floor physical therapist Matthew Durst.

In a 2007 study, patients who used biofeedback pelvic floor muscle training saw a 76 percent improvement in their symptoms, with less severe frequency and urgency, and less retention. After just six weekly one-hour sessions, some patients improve enough to stop taking their meds, Dr. Murphy says. There are no known side effects and it’s generally covered by insurance.



Illustrator Megan Berkheiser shares her MS story and a behind-the-scenes look at her art creation process. Visit [MomentumMagazineOnline.com](http://MomentumMagazineOnline.com) or download the **Momentum** iPad or Android tablet app to view this exclusive content.



■ **Botox.** Yep, the same treatment that relaxes wrinkles is FDA approved (as of 2011) to treat urge incontinence that doesn’t respond to medication or physical therapy. This in-office procedure—involving some 20 injections into the detrusor muscle (the muscle on your bladder wall that contracts to expel urine)—takes just five to 10 minutes, with results lasting six to 12 months. It works by calming some of the nerve activity connected to bladder muscles, so they’re less rigid and more elastic.

“Botox can work very well for patients who already catheterize but continue to leak urine,” Dr. Shapiro says. A 2013 study from Case Western University that reviews current data on Botox reported excellent results for symptoms of overactive bladder: incontinence, UTIs and use of incontinence pads decreased by more than 50 percent in many of the findings. Side effects, though rare, include pain at the injection site, UTIs, blood in the urine, and an increase in post-void residual urine that may require catheterization. Insurance typically covers Botox treatment (with authorization) when previous therapies have failed.

■ **Sacral nerve stimulation.** Approved by the FDA in 1997, sacral nerve stimulation (SNS) involves surgically implanting a stopwatch-sized device that acts as a kind of pacemaker for the bladder. The device sends mild electrical pulses to the sacral nerves, just above the tailbone, which control muscles and organs involved in voiding—the bladder, sphincter and pelvic floor muscles. For people with MS who have urinary retention or urinary or bowel incontinence, the device can help improve communication between the brain and the bladder, allowing messages—hey, time to pee!—to come through more clearly.

A 2012 study of the procedure on people with MS, published in the **World Journal of Urology**, showed a significant increase in voiding volume and number of voids per day, and a decrease in incontinence episodes. Side effects include pain and soreness at the incision site for up to two weeks, as well as possibly a slight tingling, tapping or pulling sensation. Complications, though rare, include pain, infection and technical problems with the device.

Medicare and many other private insurance companies cover this therapy. Out-of-pocket costs vary by insurance plan.

■ **Percutaneous tibial nerve stimulation (PTNS).**

This low-risk, in-office procedure—for people with urinary urgency, frequency or incontinence—involves placing a fine needle electrode on a spot along the inside of the ankle to stimulate the tibial nerve. That, in turn, sends an electrical pulse up to the sacral plexus, which regulates bladder and pelvic floor muscle function. “This treatment helps the nerves learn how to talk to each other instead of waiting for disrupted signals from the brain,” Dr. Murphy says. “It tells the sacral nerves, ‘You’re in charge now.’”

“I was very skeptical that this would work,” says Claire. “But this simple procedure has changed my life! Now instead of getting up three to four times a night to use the bathroom, I might get up once.”

The FDA-approved treatment, which is usually covered by insurance, reduces symptoms by 50 to

80 percent, according to Durst. “You’ll need half-hour weekly treatments for 12 weeks, and will begin to see improvement by the sixth treatment.” The most common side effects are minor bleeding, mild pain and swelling. For needle-phobes, there’s a version of the treatment that uses electrode pads.

■ **Surgery.** In the most severe cases, or if all other options fail, the final step is surgical reconstruction—to make the bladder bigger or to divert urine out through the abdomen (to an external collection bag). “My goal is to protect the kidneys, prevent infection and provide patients with the best possible quality of life,” Dr. Murphy says. “Bladder dysfunction is a fixable symptom in every case.” ■

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