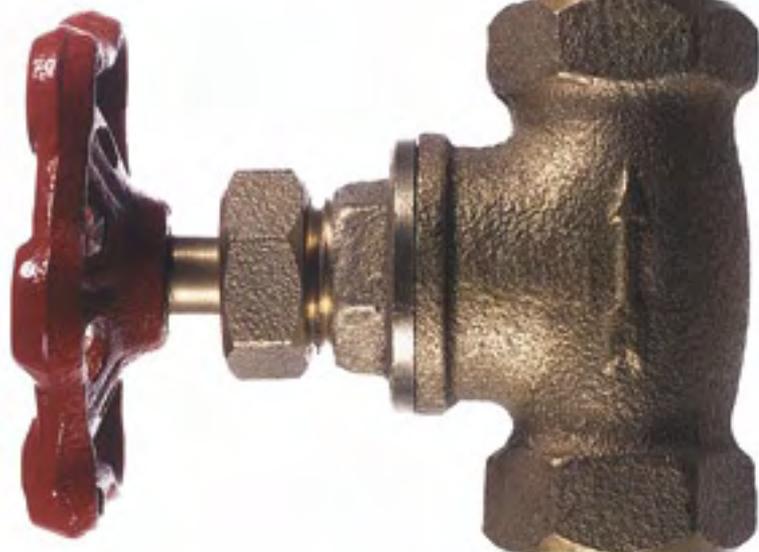


Living with an **MS Bladder**

Four people,
four stories



BY MARY ELIZABETH McNARY, MA, CRC

David Lander—known for his role as the wise-guy Squiggy in the sitcom “Laverne and Shirley”—often addresses audiences about his life with MS. He likes to open with a quip: “People make statements these days that just don’t hold water,” he’ll say. “Well, I have multiple sclerosis, so neither do I.”

Lander is on to two things about MS: Bladder problems are common, and it helps to keep a sense of humor about them. That can be a tall order in the face of the urgency, frequency, dribbling, interrupted sleep, or those “accidents” that so many of us confront.

Amanda, diagnosed with MS decades ago, analyzed it this way: “The problem is the shame. We adults are assumed to have control over our bladders, but with MS you might not have it. You can laugh about it retrospectively, but in the moment it’s very significant.”

Even children are expected to be able to “hold it.” Remember when “Just wait, honey, there’ll be a rest stop in fifteen minutes” was a reasonable request?

“Bladder symptoms may cause surprise and disgust both to oneself and to others,” Amanda continued. “You may not be able to control these symptoms, but you *can* control how you react to them, the very symptoms you have so little control over,” she laughed. “In time it’s just another problem to manage. Don’t let

shame impede your ability to deal with whatever happens.”

Amanda takes her own advice and maintains a busy schedule and a responsible volunteer job. After living with MS for so long, she has some tricks for handling an unreliable bladder. “You can be discreet and maintain your dignity by keeping the necessary supplies nearby or on your person,” she advised. She means that clean clothes, pads, diapers, catheters, medication, whatever you use, can be stashed for easy access.

“Give yourself credit for being prepared instead of reproaching yourself for needing to!” she continued. “Why waste your precious energy on regret? Just use that energy to deal with it as best you can. But make sure you don’t neglect to discuss your bladder difficulty with your doctor,” was Amanda’s final advice. “Hiding these problems in the interests of discretion is not enough. You need your doctor to know. Bladder symptoms can be hard to fix, and if you neglect to tell your health-care provider, the problems can get worse.”

Heidi Crayton, MD, assistant professor in the Department of Neurology at Georgetown University Medical Center in Washington, DC, who has many patients with MS, couldn’t agree more. “It is vitally important to the health of someone with MS to raise the issue of bladder dysfunction with their health-care provider,” she said, “so that whatever therapy is required can be initiated.”

Nancy Holland, RN, EdD, vice president of Clinical Programs at National Multiple Sclerosis Society, advocates an active “self-help partnership” between



the person with MS and the health-care professional. Working together, the most effective medical measures and management techniques can be identified and used. "There is good news for many people," she said. "These days a majority of bladder problems in MS can be managed with medications alone. But there is no partnership without good communication," she stressed.

While staying dry is everyone's goal, Dr. Holland reminds us would-be partners that we and our health-care professional may have slightly different views. "From a health-care perspective, the number-one thing is the overall health of the bladder and urinary tract. Neglected urinary symptoms can lead to serious, even life-threatening conditions, such as a systemic infection (called urosepsis)," she explained. "That's why controlling the underlying problem is the professional's first concern."

Monica, who has "but-you-look-so-good" MS, is bewildered by her bladder symptoms. "Urgency, frequency, hesitancy, incontinence, failure to void ... I've got 'em all!" she said ruefully. "How is that possible? Do I need one med to make sure I'm emptying completely, and then another to make sure I don't wet my pants? My urologist doesn't recommend an in-dwelling catheter for me, but I sometimes have to go every six minutes. How bad should it be before I start to self-cath? What are the risks associated with that? I tried to learn self-cathing once, but I couldn't find my urethra, and it hurt trying to put the tube in. I gave up in favor of pads and disposables. If I couldn't laugh about it, I'd cry; it's so confusing."

Nancy Holland explained that Monica's seemingly contradictory symptoms, like most bladder symptoms in MS, may be caused by "detrusor-sphincter dyssynergia"



or DSD. Basically, DSD is a lack of coordination between the bladder and the sphincter muscle. "In normal urination," Dr. Holland said, "the bladder contracts to expel urine at the same time the sphincter relaxes to release it. MS plaques in the central nervous system can disrupt the messages to the bladder and sphincter so they don't work together effectively.

"You don't need to have severe MS to use self-cathing. In fact, not using 'intermittent self-catheterization' (or ISC) when it's indicated can be risky," she continued. "ISC serves two goals: it provides the symptom management Monica wants and the bladder health she and her doctor seek. If she waits too long, she might end up with a flaccid bladder that overflows, resulting in incontinence.

"I would suggest that she discuss self-cathing with her doctor. If it is needed but not done, the bladder can stretch and lose its elasticity," Dr. Holland concluded.



Taking medications is one thing, but ISC requires some getting used to. MS nurse Leslie Moore said, "I always tell people to go home and think about it for a while. It really does take time to grieve before a person can see the benefit of ISC."

But what about the difficulty Monica encountered?

Dr. Holland maintains that proper self-cathing is painless, if a nurse teaches the technique.

"You can master it in a few days or at most a few weeks," Dr. Holland said. "Sometimes it helps to talk to another woman who uses ISC. For men, the mechanics are easier. They can see exactly where to put the catheter," she continued. "But they tend to have a harder time with the idea psychologically."

Len is a man who comfortably uses ISC, along with bladder pads, to manage his symptoms. "With these tools, bladder management is not such a big problem," he said. "I catheterize myself before going out."

Before learning ISC, Len stayed home rather than deal with the possible loss of control in public. "Now if I'm out, I might cath four or five times. I've been able to manage very effectively. I fit my supplies, pads, wipes, and a roll of paper towels into my backpack and go. You get used to it. I have a great, supportive family," he added. "My wife, Joan, is the best woman I've ever met."

While ISC may not eliminate all accidents, Dr. Holland pointed out that medications to control urinary frequency can be added to a plan that includes ISC. She

urges people who have frequent accidents to discuss how to manage them with their physician. "Avoiding pads altogether is often a reachable goal," she said.

Bruce, who has progressive MS, endured chronic symptoms that went well beyond the reach of ISC. And he found the medical advice he received very difficult to accept.

His urologist suggested implanting a suprapubic catheter. Bruce resisted. "The doctor said 'This will solve your problem.' But I thought, 'That's not what men do.' During the six months I debated it, I had four urinary-tract infections. The fourth one convinced me, and I've never been sorry.

"The doctor inserted a tube in my abdomen, above my bladder," Bruce recounted. "It drains into a leg bag which is hidden by my trousers. With this permanent attachment, I never feel anything. It's been my salvation. How do I keep a sense of humor about it? First, nobody knows unless I tell them. And second, I feel we're not here for very long, and life's too precious to waste a minute of it. I enjoy life too much not to stay positive despite problems associated with MS." ■

Mary Elizabeth McNary reports that she has kept her sense of humor "in continents" from North to South America and Europe to Australia, during 15 years of living with an MS bladder.

Resources

For more information on managing bladder problems, call your chapter to ask for copies of our booklets, **Controlling Bladder Problems in MS** (a basic 20-page booklet with cartoons), or **Urinary Dysfunction and MS** (a more sophisticated booklet with information on medications and diagnostic testing).

A limited supply of **Continence for People Living with Multiple Sclerosis**, from the National Association for Continence, may also be available from your chapter.

Chapter staff can refer you to MS specialists in your area or send your health-care professional copies of the Society's Clinical Bulletins, containing algorithms and professional bibliographies. **Bladder Dysfunction in MS** and **Surgical Management of Bladder Dysfunction in MS** are both available.

For an all-over look at bladder problems in MS, including hints on equipping a bathroom for safety and ease of use, go to nationalmssociety.org/spotlight-personal-care.asp on our Web site.



Suddenly, Mary's bladder becomes desperate.