Is Self-Catheterization the Answer to My Bladder Troubles? Part 1 and Part 2

by ABIGAIL BUDD

MS and Self-Catheterization

Bladder problems are a common, invisible symptom of multiple sclerosis (MS) and treatments are not talked about enough in my opinion.

I have difficulty emptying my bladder so that I sometimes need to go minutes after I've gone!

It was generally worse in the mornings, and I would go to the bathroom ten times before lunch on a bad day.This is also made worse by my mobility problems as it can be exhausting dragging myself to the bathroom all the time.

I take medication to improve symptoms of urgency, but this doesn't help if I can't empty my bladder as there's always something there that needs evacuating!

Bladder Problems Have Impacted My Life

My bladder problems have impacted my life significantly – particularly on days when I go to work. I try and time my trips to the bathroom so that I go for the last time just before I leave the house.

This gives me the maximum amount of time to drive to work before I'm desperate again. This ritual often involves sitting on my toilet at home, squeezing as much out as I can before a mad dash to the car (not easy with mobility issues thrown in).

The drive to work is around 20 minutes, depending on traffic, and when I get there, I park in the underground car park and get my mobility scooter out of the car. This involves another 10 minutes of fussing about, and by this point, I'm usually desperate for the bathroom.

The disabled bathroom is one floor up, so I'm usually jiggling up and down on my scooter, willing the elevator to appear before there's a puddle all over the floor!

The number of times I've only just made it is frightening, and I've had one or two "leakage" accidents before, leaving me with no choice but to hope no one notices.

What Could I Do About This?

I first started investigating treatments for this around five years ago and was referred to the bladder and bowel clinic for assessment. I thought they'd give me some medication and send me on my way, but I was, sadly, mistaken.

Unfortunately, the nurse wasn't the most sympathetic character and didn't fill me with confidence.

She did a scan of my bladder and had a general rummage around and concluded my pelvic floor was a mess and no wonder I was having issues. She also suggested I try Intermittent Self-Catheterization (ISC) to solve the problem of emptying my bladder.

I stared at her blankly and scratched my head as I'd never heard of such a thing. She explained ISC involves inserting a thin tube into the urethra till it reaches the bladder, enabling it to empty.

"You want me to do what?" I screeched, utterly incredulous and horrified but she talked me through it and explained how "everyone" with MS is doing it. Why had I never heard of it then, I wondered.

So, she made an appointment to come to my house and "train" me how to do it which left me shaking with anxiety. This wasn't a great success, and she asked me to contact her again when I was ready.

Was There an Alternative to Self-Catheterization?

So, I resigned myself to having to manage my symptoms myself and the above description of my morning ritual illustrates what I've been going through.

First, I restricted how much I drink to reduce the trips to the bathroom, but then I began to worry about the impact on my health.

I arrived home this summer after a long road trip, and I was so dehydrated that I was hallucinating about cups of tea and had such a blinding headache I could hardly see. Then I realized I hardly drank anything all day in preparation for the trip and this is when I called the clinic and made another appointment.

I was determined to find an alternative to ISC and was hopeful when confronted with a different, sympathetic nurse who made me feel at ease immediately.

We'd been stuck in traffic on the way so when I arrived, I rushed to the bathroom. This was good as she was able to scan my bladder and get an accurate picture of how much was left. I still had 160ml in there, but she explained that this wasn't too bad.

"What about Botox?"

I asked about Botox injections in the bladder as I hoped I'd be able to have that instead of the dreaded ISC. Apparently, you need to be able to self-catheterize if you have Botox as it can make emptying even worse, so I was faced with ISC again.

I told her my fears and stated, tearfully, that I'd just manage it myself, but she explained how dangerous this could be. Restricting what you drink can damage your kidneys and have other help implications.

She also told me that if the amount of urine left in the bladder was around 400ml, she'd have to fit a permanent catheter as there's a danger the urine can travel back up to the kidneys and cause lasting damage.

MS, Self-Catheterization and I

I was left with little choice; step up and master ISC or face the consequences.

This was when I started talking to friends with MS, and it turns out everyone does it! My friends told me that it's not so bad once you get the hang of it.

So, I started thinking about the benefits.

- How nice not to panic about where the bathroom is.
- It would be nice to go out knowing I was empty and there was no chance of an accident!
- How nice to drink large glasses of water all day long!

I can't wait to share with you more about MS and self-catheterization, and what happened when the training started!

Next page: Abi's story on MS and self-catheterization continues in part 2.

MS and Self-Catheterization: Part 2

So, unfortunately, I'm no further forwards with ISC, but this isn't due to a lack of effort on my part.

The nurse came to my house and I made all the necessary preparations; shaved my legs, had a shower and sent everyone away for the afternoon. I was a bundle of nerves when she arrived and felt sick with anxiety. It's not often that you have to expose yourself fully to a stranger and even though she's a nurse and used to it that didn't make it any less unpleasant.

At first, she showed me a film about ISC which was extremely useful. It turns out I didn't even know where the opening of the urethra was and learned so much from the drawings and then graphic demonstration.

She showed me one of the catheters that I'd be using and pointed out that there are many different types available and we could experiment till I found one I liked. Some direct the urine directly into the toilet, for example, and others have a bag attached so you can dispose of it afterward.

I was shocked at how long and large the tube was but the nurse reassured me that the opening isn't actually small which makes it easier to find once you get used to it. The tube is also lubricated to make it more comfortable to insert

"I Felt Reassured and Determined"

After this, I felt reassured and determined so off we went to my en-suite bathroom in my bedroom. I have young children in the house who wander in and out of the bathroom regardless of who's in there so it's important to have somewhere private to do the deed.

So, this is where my MS and mobility issues conspired against me! I was unable to spread my legs apart and keep them apart once sitting on the toilet.

You need both hands to insert the catheter; one to keep everything open and the other to insert it. You must also make sure the tube doesn't touch the toilet bowl as infection can be spread so easily. This made it all impossible. So she suggested I lay down on my bed whilst she examined me to see if all my bits were where they are supposed to be.

Apparently, the opening of the urethra can be much lower down, especially in women who've had babies but luckily mine was all straightforward.

I had the same issues with keeping my legs apart though and pointed out that if I used the catheter on the bed and emptied the urine into a bag I'd need my husband's help to get me back up again! Whilst my husband is a hero and supports me in most things, this is where I draw the line! I have to be able to self-catheterize independently.

"I Thought My Bladder Issues Would be Solved"

We arranged another appointment so we could try again and she promised to think about a solution to my leg

problems. She returned a few weeks later with a contraption that you fit between the knees to keep the legs apart. There was also a mirror attached so I could see what I was doing which was a revelation!

I nearly managed it a couple of times, but we had to abandon the session again as it turns out I have a prolapse which we could both see in the mirror! It was such a shock and is caused by giving birth naturally.

It can be easily fixed and I have an appointment to see a gynecologist in a few weeks. We agreed we'd resume our attempt at ISC once the prolapse has been dealt with but I can't help feeling crushed with disappointment. I thought my bladder issues would be solved and I was back to square one again!

Interestingly though, a prolapse can cause difficulties with emptying the bladder as the tubes aren't straight, so I'm hoping some of the problems will be fixed.

I was encouraged that with a little more practice I could have got the hang of it. A friend told me it took her about five months to master it entirely and now she doesn't need to use a mirror at all.

As soon as I've got the prolapse fixed, I'm determined to master ISC as the impact on my life will be enormous. I have a wedding to go to next year and am hoping to be able to sit through it without needing the bathroom during the speeches.