

My catheter-related depression and anxiety

by Brian Hines
brianhines1@gmail.com

I wish I didn't have to use a catheter to urinate. I wish I hadn't made mistakes that may have caused my bladder to become dysfunctional, leading me to need a catheter. I wish I hadn't suffered from so much anxiety and depression during the four and a half years I've been a catheter user.

But wishes are one thing. Reality is another. I'm going to be real with you.

If you're looking for a feel-good story of how a 72 year-old man has been coping with his catheterizing, look somewhere else. Sure, now I'm doing pretty well with my catheterizing. This wasn't always the case, though. So i'm not going to sugarcoat those hard times.

In a movie about the life of C.S. Lewis, Shadowlands, a student tells Lewis, "We read to know that we are not alone."

My hope is that some people who also have had problems with using a catheter will read this and realize that even though our struggles mostly are private, we share a determination to make the best of a difficult situation.

Up until the age of 68, I had no significant health problems. My family doctor would tell me at my annual checkup, "You're a poster child for growing old." I'd earned a karate black belt at age 56. I'd take my boogie board on vacations to Maui and catch big waves with the locals. I took up senior citizen skateboarding when I was 64.

I figured, wrongly, that I had many more years of good health ahead of me.

Yes, I had a prostate problem. It didn't seem like a big deal, though. I took several prostate medications. I needed to urinate more frequently, getting up several times a night. I always got an aisle seat on airplanes to ease a trip to the restroom.

Looking back, I should have realized that I needed to see a urologist. It became more difficult for me to start peeing, a different problem than having to pee too often. Yet I didn't mention this to my family doctor. I thought I was just having normal symptoms of an enlarged prostate.

Then everything changed in May 2017. My wife and I went to visit an old friend who I hadn't seen in over 40 years. We drove to the Bend area from a vacation cabin we owned with three other families in Camp Sherman, Oregon.

Before getting to his house, I thought about stopping to pee. But I didn't need to go that bad, so I drove on. Once we got there, our conversation on a deck overlooking the beautiful Deschutes River was so pleasant, I didn't want to interrupt it by going to the bathroom.

When I finally did, I couldn't go. Since this had happened before, I figured I just needed to wait a while and try again. Except, I kept trying every half hour or so, until someone asked why I was visiting the bathroom so much.

This went on until mid-afternoon. By then I really needed to pee, but still couldn't. My friend and his girlfriend told me that this was serious and I needed to get medical help. Good advice, which I didn't take.

Well, actually I did, sort of. We Googled the address of an urgent care center in Bend. Driving there, I peed in my pants involuntarily. Luckily, I'd brought along some extra clothes.

I changed in the urgent care restroom, then saw a male nurse who asked what my problem was. "I can't urinate," I said. "At least, not voluntarily." For some reason he wanted a urine sample. "Um," I told him, "I can't pee, so that's not going to happen."

He gave me a glass. "Drink three glasses of water," he said. "Then try to urinate into this bottle." I should have argued with him, but I didn't. I sat in the room by myself and drank the water. Then went into a bathroom and couldn't urinate.

By that time I was distraught. I wasn't thinking straight. I couldn't pee on my own but had wet my pants. I was frustrated, tired, fed up. Holding the empty collection bottle in my hand, I walked out and told a different nurse that I wanted to leave.

"Do you want a catheter," she asked me.

I didn't know what a catheter was. I didn't care what a catheter was. I just wanted to go back to our cabin, take our dog for a walk, and wait until I could pee on my own again. Yeah, none of that makes sense. But at the time it did, because I was so upset with how the day had gone.

“No,” I told her. “All right,” she said. “You’ll need to sign a release form absolving us of responsibility for letting you leave without treatment.” Big danger sign, in retrospect. Yet I scribbled my name on the form.

The memory of what happened in the urgent care center is as fresh today as it was four and a half years ago. I agonize over that single word that came out of my lips, “No.” What if I had said “Yes”? Why didn’t I say “Yes”? One word. One little word. Choosing one word over another may have changed my life for the worse, forever.

We drove back to the cabin. I involuntarily peed in my pants again. After all, I’d just drunk three glasses of water in the urgent care center, when I already had been unable to urinate for about ten hours.

That night I keep getting up to see if I could pee. I couldn’t. The pain was bad. As soon as the sun was up I told my wife, “I need to get medical help.” We packed up and drove two hours to Salem. I peed in my pants again. A Salem Health urgent care nurse sent me to the Emergency Room.

There I got an indwelling catheter. Several weeks later, still unable to urinate much on my own, I was told that I’d have to do intermittent catheterization. Which I still am.

Several months after my traumatic urinary retention episode, I asked my urologist if my atonic, nonfunctioning bladder would have gotten back to the way it was if I’d said “Yes” to the offer of a catheter in the Bend urgent care center.

He said, “Perhaps.” I held it together until I got into my car. Then I cried all the way home.

Almost every day since, I’ve thought about how stupid it was of me to refuse the offer of a catheter. I should have asked what a catheter was. I should have asked what would happen if I didn’t get the massive amount of urine in my bladder out. But I didn’t. And I can’t stop blaming myself for that.

My wife is a retired psychotherapist. She thinks I have PTSD, post-traumatic stress disorder. She’s probably right. However, it didn’t take long before I had an even worse mental problem: depression.

(If you’re mildly depressed yourself reading this sorrowful tale, hang in there. It’s going to end on a positive note, once I get through the anxiety and depression stuff.)

I already wasn't happy, to put it mildly, about facing a lifelong need to insert a plastic tube up up my urethra five times a day. When I started getting nighttime leg cramps, forcing me to wake up and walk around my bedroom until they went away, then doing this again a few hours later all night long, the lack of sleep helped push me into a full-blown depression.

Not fun. At first I just thought I was tired. And sad about my non-functional bladder. Then my wife said, "No, you're depressed." She was right.

I had no interest in doing things I used to enjoy, like write posts for my three blogs. From being afraid of dying, I started to think that, hey, death wouldn't be so bad. At least I'd be free of feeling like I was in an emotional black hole with no exit sign.

My urologist's office said there was no way the leg cramps could be related to my bladder problem. I pointed out that I'd never had leg cramps before, and now I did, shortly after starting to use a catheter.

Fortunately, I was able to see a Sleep Clinic physician. After being prescribed gabapentin, the leg cramps went away. I also was fortunate that my primary care doctor's office had a psychiatric nurse practitioner. She diagnosed me with Major Depression, Single Episode.

So I now had a mental health diagnosis to add to my growing list of physical problems. I was prescribed an antidepressant, which over several months helped me climb out of the black hole I was in, along with counseling sessions with a social worker.

Depression was in my rear view mirror. Unfortunately, catheter-related anxiety was in the passenger seat right next to me, where it still sits. Worse, sometimes anxiety feels like it's taken my place in the driver's seat — though gradually I've gotten better at keeping anxiety's hands off of my mental steering wheel.

I don't know whether the frequent trouble I have getting a catheter to pass into my bladder is typical for many men, or atypical. Regardless, this has been my biggest longstanding problem.

In the early days I'd call my urology clinic and talk with the nurses who worked with my doctor. "I'm having trouble inserting the catheter," I'd say. "Do you have any tips?" I'd be told to take a shower, go for a walk, or wait a while and then try again.

OK, but I wanted to get back to what I'd been doing before my bladder stopped working like it should. Eating out. Going to a movie. Visiting friends. If I went into a restroom at a restaurant to do my catheter thing, then found I couldn't insert it, obviously taking a shower wasn't an option.

And I didn't want to interrupt a meal with friends by saying, "Sorry, I've got to go for a walk and then see if I can get a catheter into my bladder." Not exactly a great dinner conversation topic.

Not being able to insert a catheter at bedtime was the worst. I was tired. I wanted to sleep. I needed to urinate. Yet sometimes I'd spend an hour or more lying on the bed, trying to relax with breathing exercises, so the damn catheter would pass into my bladder.

To make a long story short — and this story *really* is long — at times I got extremely frustrated and angry. My wife had to put up with quite a few outbursts where I'd either start crying or slam doors or both, because I was having such a difficult time inserting a catheter.

I'd try catheters other than the Flex Coude Pro that I'd come to know and love. (Well, except when I couldn't get it into my bladder.) But none of them were anywhere near as comfortable and easy to use as the Flex Coude Pro, so I stuck with it.

Eventually I had the bright idea of trying a smaller size catheter, FR12 or FR10 rather than FR14. Often I could insert one of those when the FR14 wouldn't go in.

Even so, I still am anxious about traveling or going anywhere where I might need to use a public restroom. I haven't flown since I started using a catheter. I haven't driven by car more than two hours from where I live.

If I could be confident that popping in a catheter would go smoothly, I'd be hugely happier. That would allow me to view myself as simply differently-abled in how I pee. However, not knowing when I'll have trouble inserting a catheter — I haven't been able to predict when this happens — makes me anxious.

And when I have a particularly difficult time, my mind generates flashbacks to the traumatic day and a half back in May 2017 I've described. It must be similar to a war veteran hearing fireworks and feeling like it's a roadside bomb. When I'm unable to insert a catheter, sometimes I feel panicked, like I did when I couldn't pee at my friend's house or in the urgent care center.

However, I don't want to leave the impression that I'm a total catheter train wreck. I've learned a lot over the years. Most days now, things either go smoothly for me, or I'm able to handle occasional problems inserting a catheter with no freakout.

I've accepted the fact that almost certainly I'll have to use a catheter for the rest of my life.

My bladder has recovered some function, but nowhere near enough, I strongly suspect, to ever justify prostate surgery. I got a second opinion from a medical school urologist who told me, bluntly, "You don't have a prostate problem, you have a bladder problem."

However, I always thought I had a prostate problem. It never occurred to me that my bladder might stop working one day, and my primary care doctor didn't bring up this possibility.

I haven't stopped regretting walking out of the urgent care center in Bend. However, I do my best to tone down that regret by focusing on a couple of things that allow me to fashion a story which doesn't have me as the Bad Guy as regards my non-functional bladder.

First, my urologist said that not getting medical care sooner *could* have harmed my bladder's ability to recover from the urinary retention episode. *Could*. This isn't certain. So regardless of how I acted that day, I might well have still needed to use a catheter.

Second, during a cystoscopy (scoping of my bladder) by the second-opinion urologist, he said, "Look at that pocket in the bladder wall. That was caused by the bladder trying to push urine through your prostate for a long time."

A long time. Those words imply that my bladder was gradually losing functionality for quite a few years, so slowly that I viewed this as a normal part of aging for a man with a prostate problem.

It's difficult, but I'm learning to forgive myself. After all, there may not be much to forgive.

I try to remember that life is difficult for everybody, and I'm more fortunate than many. As my wife frequently reminds me, I'm pretty damn healthy overall. I use a chainsaw on our ten rural acres. I put 40 pound bags of salt in our water softener. I can bicycle, lift weights, do Tai Chi.

Life isn't over just because I have to use a catheter five times a day. As I've described, there were moments when I thought life wasn't worth living. Now, though, I'm almost as happy as I was before.

Almost. And that's good enough for me, especially given the much darker days I went through with my catheter-related depression and anxiety.