

The Complications I Didn't See Coming

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[00:00:09] Hello, and welcome back to Leaks, Laughs, and Life with a Urostomy. I'm your host, Dawn. And if you're new here, this podcast is all about real life after bladder removal: the good, the messy, the funny, and everything in between.

[00:00:24] Before we dive in, I want to gently remind you that I am not a medical professional. Always speak with your surgeon or medical team about decisions regarding your own care.

[00:00:35] My goal here is to simply create a safe space to laugh, learn, and feel a little less alone.

[00:00:42] I am sharing my lived experience from my own urostomy journey and from my husband Alex's neobladder journey because bladder-free living comes in many forms, from leak disasters to travel hacks, from emotional hurdles to unexpected victories.

[00:00:59] Thank you for [00:01:00] being here, it tells me you showed up on purpose, and that means more than you know.

[00:01:05] There's a version of surgery that gets explained to you, and then there's the version you actually experience. And sometimes those two look very different. Before my surgery even really began, there was already a complication.

[00:01:24] I had too much scar tissue in my abdomen.

[00:01:27] So much for the little incisions. Hello, gut zipper.

[00:01:31] Before Dr. Wilson could even begin the regular surgery, she had to clear scar tissue before she could actually get into removing my bladder. Two and a half hours later, she was finally able to begin the radical cystectomy.

[00:01:48] That is one of those things you do not think about ahead of time. You think about the surgery. You do not think about what might be standing in the way of it.

[00:01:57] And that set the tone for what was coming next [00:02:00] because my body had a few more surprises.

[00:02:03] After surgery, my intestines decided they were not interested in participating in this recovery process, and they went on vacation. When that happens, everything backs up, and in my case, bile was backing up into my stomach. Now, I'm laughing because It's not funny when it happens at the time, but looking back, it was like a comedy of errors.

[00:02:29] So I had the option of going back into surgery, or they could insert an NG tube. I had no idea what that was at the time. I just knew I didn't want more surgery. And if you do not know what an NG tube is, once you get one, it's not something you will ever forget. I had that tube in for five days. It goes in your nose and down your throat into your stomach.

[00:02:54] I had five days of waiting for my body to decide it was ready to start working again. [00:03:00] Five days of not eating, just five days of being in it, and that extended my hospital stay from what was supposed to be four days to eight. Even after being discharged, I stayed in Denver for another week just to make sure there weren't any more complications.

[00:03:18] Because at that point, you realize things do not always go according to plan.

[00:03:23] I lived two hours away from the hospital and from my doctor, and so I wanted to stay in Denver to be close in case something else happened.

[00:03:31] For weeks after I got home, I could not eat normally. It was sweet potatoes, mashed potatoes, pudding, Jell-O, popsicles, foods that were soft and easy on my system, but ugh, I was so sick of them by the time I was able to finally start eating something a little more solid.

[00:03:53] That was all I ate, and I ended up losing about 15 pounds, which was great. Sounds like a great [00:04:00] number, but it was really a reflection of how limited everything was at that time.

[00:04:05] About a month after I got home, something else started to happen.

[00:04:10] My hair began to fall out, and not just a little bit. I'm talking handfuls and handfuls.

[00:04:17] I woke up one morning and brushed my hair, and I about fell over ...

[00:04:24] because of the amount of hair that was in the brush. And I emptied out the brush, and I started brushing again, and I got another brush full of hair. I was just shocked, is the only way to put it, and I was almost in tears. And it's one of those moments where you just stand there and think, "Really? We're doing this, too?"

[00:04:51] I was told it was likely from the anesthesia or possibly a combination of that and the estrogen patch that I had been put on. So, my doctor [00:05:00] agreed with me. I stopped the estrogen patch. And then I waited. I waited for a dermatologist to call, only to find out two weeks into the waiting that there were no dermatologists in my area that dealt with hair loss.

[00:05:15] And the ones that did, well, they were over an hour away and would not accept my insurance.

[00:05:22] So I was pretty much on my own to figure this out. Fortunately, with my functional nutrition background, I knew I had to figure this out. I was not going to go bald, and that is where this was heading. I researched, and I increased my supplements: magnesium, copper, vitamin D, and K3, B12, and selenium.

[00:05:48] I changed shampoos, and I waited. Because that is what so much of this process is. You adjust, and then you wait to see what happens.

[00:05:59] It took over [00:06:00] a month for the hair loss to stop, and I lost so much hair during that time, baggies full. I literally was saving a daily bag of hair to show in case I did find a dermatologist, in case it didn't stop falling out, so that I would have proof.

[00:06:19] And then it slowly started growing back in. I had these little bitty fuzzy sprouts, which sounds like a win, and it is, but it came back different.

[00:06:31] About, mm, maybe three weeks into the growth coming back, I started to notice it was curly, very curly, and was very soft, kinda like a baby bird's down feathers coming in under my straight hair.

[00:06:48] I looked like a bird going through a molting phase, which honestly felt pretty accurate at the time. And oh, I still to this day laugh because the vision of it, [00:07:00] like on the back of my neck, it was just fuzzy.

[00:07:03] It was crazy.

[00:07:06] And then there was the UTI.

[00:07:08] This one was different because this one could have gone very wrong.

[00:07:13] I did not know what symptoms to look for. I was told UTIs might be a thing, but not what that might look like or feel like.

[00:07:23] So when I started feeling off, I did not connect the dots right away.

[00:07:28] At first, I thought it was strep throat because my son had been sick with strep, but my throat wasn't sore. I just felt weak for the first couple of days.

[00:07:39] And then the 102 and a half degree fever hit, and then the side pain, and it kept building. I felt worse and worse. I called my surgeon, but she happened to be out of town, and the office staff had left a message for the attending doctor.

[00:07:55] So I waited and waited, and I didn't hear anything back that day.[00:08:00]

[00:08:00] So the next day, I called first thing in the morning. I had had a stabbing pain in the middle of my back and knew something was off. I called the office again and finally was able to talk to someone. She told me to get to the ER immediately.

[00:08:15] Thank goodness for the attending PA in the ER. He understood urostomies. Thank you, Matt. You were a lifesaver. He knew exactly what to do. He jumped into action, drew blood, did a proper urine sample, not just pee-in-a-cup one. Um, he did a CT scan, and then he started an IV of strong antibiotics and fluids.

[00:08:41] Four hours later, he told me that I was only a couple hours away from going septic, and that is not something you forget. Not because it was dramatic in the moment, but because of how easily it could have been missed. That was a turning point for me because it made me realize [00:09:00] that there

is a gap, between what you are told or not told and what you actually need to know to live this life with a urostomy safely, and that gap matters.

[00:09:13] All of these complications, they were not part of the plan. They are not normal.

[00:09:19] They are not part of the version of surgery that gets explained ahead of time, but they were part of my reality.

[00:09:25] It took about five months before things really started to feel better,

[00:09:29] before my body started to stabilize, before it felt like I was not just reacting to one thing after another, after another.

[00:09:37] And I think that's important to talk about because when people hear surgery and recovery, there's often an expectation that things will follow a timeline.

[00:09:49] There is no timeline. You don't necessarily move forward in a predictable way, and sometimes recovery is like a plot twist.

[00:09:58] You think you're headed in one [00:10:00] direction and you're handling one complication, and then another one decides to pop up. You're just trying to figure out what your body needs next.

[00:10:10] These become moments of progress, small ones, sometimes quiet ones, and those are the moments that carry you through.

[00:10:20] Thank you for joining me today on Leaks, Laughs, and Life with a Urostomy.

[00:10:24] I hope this episode gave you a few insights, a few laughs, and reminded you that you are not alone in this journey.

[00:10:32] If you found it helpful, please subscribe so you don't miss an episode and share it with someone who might need to hear it.

[00:10:39] More information, tips and tricks, or a copy of the show notes, please go to my website at leakslaughslife.com, or you can connect with me on Facebook, Instagram, LinkedIn or YouTube. I would love to hear from you.

[00:10:57] You can also find my books, [00:11:00] "Leaks, Laughs, and Life with a Urostomy: The Handbook", and "My Plot Twist Journal" on Amazon. Together, they are designed to support those who are either new to life as a urostomate, who are preparing for surgery, or supporting someone who is.

[00:11:18] Next week, we are going to get into the day-to-day side of things: what to eat, how to stay hydrated, ways to help manage gas and mucus, and my daily routine and supplements that I use to help prevent UTIs.

[00:11:34] Until then, take care of yourself and be gentle with your body. And remember, this journey has its share of leaks, plenty of laughs, and a whole lot of life. Bye for now.