

## 12. My New Normal: One Year Later

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[00:00:09] Hello, and welcome back to Leaks, Laughs, and Life with the urostomy. I'm your host, Dawn, and if you are 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. Please always speak with your surgeon or medical team about decisions regarding your own care. My goal here is simply to create a safe space to laugh, learn, and feel a little less alone.

[00:00:43] I am sharing my lived experience from my own urostomy journey, and also 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. [00:01:00]

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

[00:01:07] One year ago, I did not know what my life would look like on the other side of my bladder eviction. I had no idea what normal would be. I didn't know what I'd be able to do or not to do, and if I'm being honest, I wasn't totally convinced things were going to feel good again. But here I am one year in.

[00:01:28] And today I want to talk a little bit about what that actually looks like, the good, the messy, the oopses and all of it.

[00:01:36] Let's begin with the day of surgery. Honestly, it was rather hysterical.

[00:01:41] I remember when it was getting close to time for me to go into the operating room. They had already given me the drugs to knock me out, but of course, they hadn't quite kicked in yet. And of course, I had to go to the bathroom again... as I got up and was moving towards the bathroom with all the [00:02:00] IVs attached and my little wiggly cart. I saw Dr. Wilson coming down the hall and not thinking I ran towards her and gave her a huge hug and thanked her for doing this surgery. But what I didn't realize was that in the process, I had ripped out one of the IVs out of my arm and there was blood spurting all over the floor and on me, and Dr.

[00:02:22] Wilson was like, oh, calm down. Calm down. It's okay. And she signaled to the nurse to quickly guide me into the bathroom. And I vaguely remember singing, "Dingdong, the Bitch is Gone," which she wasn't yet. But of course, I was referring to my bladder and I remember being in the bathroom, the nurse helping me get cleaned up and then getting back into that bed and Alex saying, I love you.

[00:02:48] And then I woke up about six and a half hours later. And when I woke up, Alex had a really concerned look on his face. I barely remember asking him, did everything go okay? [00:03:00] And he was like, "well, not exactly, but Dr. Wilson worked her magic, and you were all good."

[00:03:07] Apparently the two-and-a-half-hour surgery turned into a five-and-a-half-hour surgery and what was supposed to be a few small incisions.

[00:03:15] It turned into one very large incision my body creates scar tissue like its training for the Olympics, and Dr. Wilson was not able to get the robotic arms into my abdomen, so she had to go old school. She spent a couple hours clearing the scar tissue before she could even start the actual surgery.

[00:03:34] Now, the first week I was supposed to be in the hospital for four days. I was there for eight. My intestines decided they were on vacation, and instead of taking me into surgery again, they decided to insert an

NG tube through my nose to drain my stomach because things were not moving. Five days later, my digestive system finally woke up and rejoined the [00:04:00] party.

[00:04:00] There's no other way to say it. Everything felt uncomfortable, but the upside was the excruciating pain that I had before was gone. And for the first time in 11 years, there was no urgency to pee. There was no stabbing, excruciating pain or constant bladder spasms, and that part was absolute heaven.

[00:04:24] I spent the second week at my papa and my stepmom's house in Denver so that if something went sideways, I would be close to the hospital and that's when my papa told me, "you are going to help a lot of people."

[00:04:34] And I had no idea what he meant at the time.

[00:04:37] I'm so grateful for them being there. They assisted in taking care of me so I could just rest. And boy did I revel in the sleeping part. I had not slept more than 15, 20 minutes at a time for the two years prior to the surgery.

[00:04:54] And I slept nine to 10 hours straight. It was absolute heaven.

[00:04:59] The [00:05:00] first few months when I got home were quite overwhelming. They were frustrating and emotional on every level. The realization that life was going to be different, it really hit home. And that's when I discovered that there was no lived experience assistance out there on how to live with your urostomy.

[00:05:22] And I began to understand how I could help others going through this process. And that's when my dad's voice kicked in, and later things started falling into place.

[00:05:32] In the meantime, I was figuring out how to sit, how to walk. How to sleep with that big hose attached to my side that wanted to do all-star wrestling in the middle of the night and try trying to maneuver a pouch that was too large for my body.

[00:05:48] Everything took so much effort and I was completely exhausted just getting up and going to get water or to do my little walk to the mailbox. And I do mean [00:06:00] little.

[00:06:00] It was exhausting.

[00:06:02] Changing my pouch took forever. I remember the first couple times it was like 45 minutes to an hour. And Stella, my stoma, had absolutely zero interest in cooperating. She made it her personal mission to make sure that pouch changes were very interesting, and they were.

[00:06:21] And then there was the hair loss. And I'm not talking about a little bit of hair loss. I am talking about handfuls and handfuls falling out every day for over a month.

[00:06:33] Now, whether it was the anesthesia or hormones, we never really figured it out fully, but eventually. I stopped the estrogen patch and started doing everything I could to help my hair recover. And thankfully it did.

[00:06:50] Around month four, I started to feel better than I had in a long time. It was like a breath of life came into me. I started venturing out more. [00:07:00] Short walks, going to the store, out to dinner. It was terrifying, but also freeing at the same time, and this is when I also learned the hard reality about UTIs. I was sick for a month, and I was a few hours away from going septic.

[00:07:19] I was totally clueless about the danger of UTIs. Hard lesson learned on that one. I do have a whole episode on UTIs. I think it's episode number six. If you have questions about UTIs, please go listen to that one.

[00:07:35] And then month six. Brought a bunch of small wins. It was one of the first times when I left the house. I didn't feel completely on edge the whole time I was out there.

[00:07:47] I wasn't dreading having my pouch leak, it finally began to feel somewhat normal, I guess is the way to explain it. And I felt like an engaging in activities other than just sitting and resting and [00:08:00] walking.

[00:08:00] And that was also the month that I think I finally came out of the depression that I had been in and was figuring out how to deal with the emotional side of the surgery because that was really hard. I didn't want to talk to anybody. I didn't want to see people. I really just wanted to be left alone, and if you know me, that's, that's not me.

[00:08:23] Month eight was a big one. It was the first time I had sprung a leak and instead of panicking, I handled it and then went on about my day, like it was nothing. And honestly one of the biggest milestones was the first time I forgot about the fact that I was even wearing a pouch. And then I realized, "wow, this is becoming normal!"

[00:08:47] And then there's of course the "oops" moments. Oh yes, there were plenty of those.

[00:08:52] Horrible timing. Stella, thank you so much for the challenges.

[00:08:55] Like the time I sprung a leak when I was driving, pulled [00:09:00] over to a gas station bathroom, and of course it was gross. There was no counter space. So there I am sitting on the toilet with a paper towel across my lap and all my supplies teetering on my lap, praying they don't fall in the toilet or on the floor trying figure out where this leak is, and being able to stop the leak very quickly with one of my barrier strips, and then I was able to pack up all my supplies and get back on the road.

[00:09:29] And then there was the leak at work when my survival kit was out in my car instead of with me. Lesson learned on that one.

[00:09:37] And let's see what other, oops moments?

[00:09:40] There was one where I tried the new type of pouch. I tried a one-piece pouch and then decided, "oh, I think it'll be a good idea to go shopping."

[00:09:50] Well, Stella decided she didn't like that pouch and literally blew it off my tummy. And so, I was driving with a diaper stuffed into my pants [00:10:00] until I got home so that I could stop the leak because I didn't have a way to put the bag back on.

[00:10:06] And then there's the 2:00 AM and 3:00 AM Gushers, you know, from Old Faithful where you wake up in the bed is soaking wet.

[00:10:14] Thank God for bed protectors, because those saved me from having to sleep on the floor a couple nights. Uh, I'm glad those were far and few between.

[00:10:25] You know, a year ago these moments completely threw me for a loop and now, you know, I might roll my eyes and maybe laugh a little. I handle it and then I move on, and it doesn't blow my whole day when those happen anymore.

[00:10:42] And that shift is huge.

[00:10:46] So I guess this is my new normal. It is real.

[00:10:50] I have routines now. There's more planning. I don't leave the house without my survival kit, and there's always a [00:11:00] change of clothes in my car and enough water to get me through my day so that I don't get dehydrated, so that I don't get UTIs.

[00:11:08] And I've learned to be able to time my fluid intake to correspond with my pouch changes. So Stella and I don't fight each other and we're down from 45 minutes to about 10 minutes to change out the whole system goes pretty quick now, and it's not overwhelming anymore. It's just part of life.

[00:11:31] It's my new normal, like grabbing your phone, you're grabbing your keys, always grabbing your survival kit too, and the confidence that comes with that. That's something I didn't have in the beginning, and this is the part that really stands out to me. I have my life back. I can go places, I can make plans, I can travel again.

[00:11:55] I can actually enjoy what I'm doing instead of constantly managing [00:12:00] symptoms or worrying about what might happen. And hallelujah, I can sleep!

[00:12:05] Is everything perfect? No, not always, but the majority of the time, life is good and that feels really, really good.

[00:12:17] So if you're at the beginning of this or somewhere in the messy middle, please know it does get easier, not all at once, but little by little you begin to figure things out.

[00:12:29] Before we wrap up today, I have a request. If you've had surgery recently and maybe you're also at your year mark, I would love to hear your stories, so please share them with me. You can email me at Dawn, DAWN@leakslaughslife.com. That's L-E-A-K-S. L-A-U-G-H-S as in Sam, LIFE.com because in an upcoming episode, [00:13:00] I am going to be celebrating real wins from people living with urostomy. The big wins, the small wins, the funny and messy ones. Let's celebrate them all together.

[00:13:10] If you have questions, there's also my book that I just released, Leaks, Laughs, and Life with a Urostomy: The Handbook, and My Plot Twist Journal that goes along with it. They're both available on Amazon and they have lots of information in them to help you make it through this journey a little bit easier.

[00:13:37] So thank you for joining me today on Leaks, Laughs and Life with a Urostomy. I hope this episode gave you a few insights, maybe a laugh, and reminded you that you're not alone in this journey. And 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.

[00:13:56] For more information, tips and tricks, or a copy of the show notes. [00:14:00] Please go to my website@leakslaughslife.com. Next week we're going to be discussing how to deal with those lovely hoses and the nighttime bags that go with them, and maybe even the leg bags, my arch nemesis. And until then, take care of yourself.

[00:14:20] Be gentle with your body. And remember, this journey has its share of leaks. Plenty of laughs and a whole lot of life.