

Episode 1: How I Got Here, And Why You're Not Alone

[00:00:00] Leaks happen, but life doesn't stop and neither do we.

[00:00:06] Welcome to Leaks, Laughs, and Life with the urostomy.

[00:00:09] I'm Dawn, a wife, mom, artist, and a Urostomate.

[00:00:14] If you're preparing for bladder removal surgery, newly bladder free, living with a urostomy or a neobladder, or loving someone who is, you're not alone and you're in the right place.

[00:00:26] So grab your cup of coffee or tea and settle in.

[00:00:32] Sitting here talking into a microphone about my life still feels a little surreal. I never imagined I'd be sharing the story of my bladder being evicted, or learning to live with a urostomy or navigating a body that had to be replumbed.

[00:00:49] This podcast exists because nothing like that existed before my surgery.

[00:00:55] There was nothing to prepare me for the real lived experience of life
[00:01:00] after this surgery, only the medical descriptions.

[00:01:04] But here we are, and if you're listening, chances are you didn't plan this life either.

[00:01:10] This space is for people who feel like they fell into a life they never signed up for, and for those who need practical tips and emotional validation at the same time. And it's for anyone who wants honesty without doom, hope without toxic positivity.

[00:01:25] And maybe a laugh or two along the way.

[00:01:28] My journey with interstitial cystitis started years before most urologists even knew it had a name. For a long time, I was misdiagnosed, tested, retested, treated for things I didn't have all while, living in constant pain. IC is an autoimmune disease that attacks the bladder and it brings relentless urgency,

painful spasms, and excruciating pain. And exhaustion that [00:02:00] seeps into every corner of your life.

[00:02:03] Eventually, the doctors found nine tumors and then they were removed. I felt better briefly, and then the pain came roaring back with a vengeance. At this point, my life revolved around bathrooms, food restrictions, and survival mode.

[00:02:23] In 2022. Life threw my husband and I a curve ball.

[00:02:30] My husband Alex, was diagnosed with borderline stage four bladder cancer. I watched him go through chemo and then a radical cystectomy and watched him as he navigated learning to live with a neobladder. I am so proud of him and how he has regained his independence.

[00:02:49] What most people don't realize is how rare it is to have real support before surgery and after surgery. I had it to a certain extent because Alex and I were walking parallel [00:03:00] paths. The exception was that his was internal. While I chose to have the pouches on the outside, I really didn't understand what I was getting myself into, and the tiny bit of information that was available did not prepare me for what I was going to be experiencing afterwards.

[00:03:20] By late 2024, my IC had reached end stage, which is called Hunner's lesions. I wasn't sleeping. I was lucky to get like 10 to 15 minutes at a time, living through constant spasms and pain that broke me down physically and emotionally. I had yet another procedure to cauterize the Hunner's lesions, and that relieved some of the pain for about maybe two months.

[00:03:48] Alex and I went to a follow-up appointment after that procedure, and my doctor began explaining the next treatment option and my husband asked quietly, "didn't you say if this didn't [00:04:00] work, you could remove her bladder?" And the doctor looked at me and gently said, "oh, I thought she might wanna try some more options first."

[00:04:09] I broke down. My husband could tell that I was, I was at my wit's end and I looked at her and said, "can you just take it out, please? I can't live like this anymore."

[00:04:25] On April 14th, 2025, my bladder was officially evicted. I began singing Ding dong. The witch is gone. You, you know the tune. I'm not gonna sing anymore.

[00:04:38] The reason I chose a urostomy was because I never wanted to have to pee another day in my life. I had already done enough of that for 20 lifetimes.

[00:04:47] The surgery was far more complicated than I expected. And for those of you heading into this surgery, that is not normal, just to, you know, give you some [00:05:00] hope.

[00:05:00] My recovery was slow. There were complications. And again, those are possible, but again, not normal. And there were days that I asked myself, "what have I done?"

[00:05:14] But then, I slept through the night for the first time in over 11 years. I stood up and I had some pain from the surgery, but my insides did not feel like they were being ripped out anymore.

[00:05:30] It was so amazing!

[00:05:33] And I laughed at leaks that shouldn't have been funny, but somehow were, and slowly, carefully, I began to trust my body again.

[00:05:44] Life with a urostomy wasn't an ending for me.

[00:05:47] It was a whole new beginning, and I would do it again every single time.

[00:05:54] The reason I'm doing this podcast is for people who are facing bladder removal surgery [00:06:00] or those newly living with a urostomy or neobladder, their caregivers, partners and loved ones, or anyone living with chronic illness.. So that those people can have the practical tips and emotional validation.

[00:06:16] And for those who want honesty, not sugarcoating and maybe a laugh or two, when things get messy and oh goodness, they will.

[00:06:24] In future episodes, we'll talk about day-to-day life with a urostomy or a neobladder. Leaks. Yeah, the dreaded ones and body image, intimacy and identity, the stuff no one warns you about and the tiny victories that feel enormous when they happen.

[00:06:44] For the next episode of Leaks, Laughs, and Life with a Urostomy, we'll be diving into urostomy versus neobladder, the medical pros and cons, and the real life version pros and cons.

[00:06:58] In closing, thank you for [00:07:00] being here. It tells me you showed up on purpose and that means more than you know.

[00:07:05] Let's navigate this unexpected life together.

[00:07:08] Until we meet again... please take care of yourself. Be gentle with your body and remember, leaks happen, laugh anyway.

[00:07:19] For more information, please visit my website@leakslaughslife.com.

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