

9. Why Someone Might Need Bladder Removal

[00:00:00] So... bladder eviction. Not exactly the life plan, right?

[00:00:06] But there are real reasons it happens. And today we're going to talk about them.

[00:00:11] Hello and welcome back to Leaks, Laughs, and Life with a Urostomy.

[00:00:16] I'm your host, Dawn.

[00:00:18] 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.

[00:00:28] Before we dive in, just a quick reminder that I am not a medical professional. I am sharing lived experiences 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.

[00:00:48] Please always speak with your surgeon or medical team about decisions regarding your own care. My goal here is to simply create a safe space to laugh, learn, and feel a little less [00:01:00] alone.

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

[00:01:07] Today we're talking about something really important, especially if you are at the beginning of this journey or about to begin this journey.

[00:01:14] Why would someone need their bladder removed? Because this is not exactly a casual life decision. Nobody wakes up one day and thinks, you know what sounds fun? Let's remove an organ.

[00:01:25] There's always a reason, and usually it is a serious one. The most common reason is bladder cancer. For many people, like my husband's, this surgery is lifesaving. It is not optional. It is necessary to remove the cancer and prevent it from spreading.

[00:01:42] And when you hear that word cancer, everything changes instantly.

[00:01:50] Your focus shifts from how will I live to I need to live? And that perspective matters because while the adjustment [00:02:00] afterward is real, the surgery itself is often what gives someone more time, more life, more moments that they would not have had otherwise.

[00:02:10] Another reason, and this is my story, is interstitial cystitis.

[00:02:15] This is not just a bladder that hurts sometimes. This is a chronic, daily, relentless pain with urgency, frequency, and discomfort that can take over your entire life, and it did mine. You plan your day around bathrooms. You lose sleep. If you're able to sleep at all. You cancel plans because you can't do anything but be in the bathroom.

[00:02:40] You start to feel like your whole world is getting smaller and smaller.

[00:02:45] And with every treatment that has been tried and nothing working, bladder removal becomes an option. Not because you want it, but because you want your life back, and that is something people on the outside do not always [00:03:00] understand.

[00:03:01] There are also neurological conditions like multiple sclerosis or spinal cord injuries.

[00:03:06] In these cases, the bladder may not function properly at all. It might not empty. It might retain urine, which can lead to infections or kidney damage. So the issue is not just inconvenience, it becomes a safety concern, and at that point, doctors are looking for long-term health and protecting the body as a whole.

[00:03:25] There are also other situations like severe trauma, radiation damage or complications from other conditions where the bladder is simply no longer able to do its job.

[00:03:37] At that point, the conversation becomes less about if and more about what is the safest way forward.

[00:03:47] No matter the reason, once the decision is made or that surgery happens, you are suddenly living a completely different life. And no one really prepares you for that part.

[00:03:59] [00:04:00] Yes, you get medical instructions from your doctor. Very basic instructions I might add.

[00:04:09] And yes, you get supplies, but what about real life?

[00:04:13] What about standing in your bathroom for the first time, trying to figure out your pouch system and thinking, am I doing this right? Did I forget anything?

[00:04:22] What about your first leak?

[00:04:24] What about getting dressed and realizing your old clothes, that used to fit wonderfully, do not quite work the same way anymore.

[00:04:34] These are the parts that people are often left to figure out on their own.

[00:04:38] And this is exactly why I wrote my book. Leaks, Laughs, and Life With a Urostomy: The Handbook, because I remember being in that place of figuring it out as I went.

[00:04:50] I searched everywhere for information. Websites, YouTube, medical forums. I even asked people I thought might know about [00:05:00] them and I came up empty.

[00:05:02] It was like trying to find a unicorn in the desert. Nothing felt honest, nothing felt helpful, and everything made me more confused.

[00:05:11] I needed a guide. I needed a friend and a roadmap through all the messy, awkward, and sometimes hilarious moments would've been really wonderful.

[00:05:22] So I put everything I wish I would've known into one place.

[00:05:27] Things like what questions to ask before surgery. Because some things you just don't think of until it's too late.

[00:05:33] Like, wait, where's my stoma going to be living?

[00:05:36] What no one tells you, but should.

[00:05:38] The emotional stuff, the awkward stuff and the, oh crap. Did that just happen? Stuff.

[00:05:44] How to actually change your pouch calmly without turning it into a full blown production worthy of a TV reality show. Uh, 'cause it can get a little insane sometimes.

[00:05:55] There's information about Leak Management 1 0 1, and yes, leaks
[00:06:00] happen and yes, you will survive them.

[00:06:02] There's a section on rebuilding confidence and feeling like yourself again. Even when your body suddenly has been creatively re-plumbed.

[00:06:10] Clothing travel, and returning to work. I talk about tips to keep you stylish and help you through the workday and what to say when things get a little bit tricky.

[00:06:21] I talk about when things go wrong sometimes hilariously, because if you can't laugh at it, you'll just cry and sometimes you end up doing both because that's all a part of the urostomy life.

[00:06:34] The book will be available for purchase on Amazon on Tuesday, March 31st. It is truly written from lived experience, not theory, and not a medical perspective.

[00:06:45] If you are facing bladder removal or living with a urostomy or neobladder, I want you to hear this, clearly. There is life on the other side of this. It may look different. It will take [00:07:00] time, a lot of time to heal, but different does not mean worse. And for many people it actually means relief. It means freedom from pain, from constant urgency. From fear of what's happening inside their body, and over time you adapt, you learn, and you'll find your rhythm again.

[00:07:23] Before we wrap up, I am working on an upcoming episode about listener stories and wins. Big wins, small wins, funny wins, messy wins. If you have something to share, please send me an email. At dawn@leaksLaughslife.com.

[00:07:40] That's DAWN at leaks. L-E-A-K-S, Laughs, L-A-U-G-H-S life L-I-F-E.com. Let's celebrate these wins together. I'd love to share your stories.

[00:07:59] Thank you for [00:08:00] joining me today on Leaks, Laughs, and Life with a Urostomy. If you found this helpful. Please make sure you subscribe so you don't miss an episode, and share it with someone who might need to hear it.

[00:08:10] For more tips, resources, and updates on the book release, head over to leakslaughslife.com. In the next episode of Leaks, Laughs, and Life with Urostomy, I'll be sharing a bit more information about what's in the book, Leaks, Laughs, and Life with the Urostomy: The Handbook.

[00:08:31] And remember, this journey has its share of leaks, plenty of laughs and a whole lot of life.

[00:08:38] So until next time, take care of yourself. Be gentle with your body, and I will see you next week.