

Mental Health After Bladder Removal

[00:00:00] After surgery, the physical healing gets attention, but the mental and emotional, that side is where things really shift.

[00:00:10] Hello and welcome back to Leaks, Laughs, and Life with Urostomy.

[00:00:13] I'm your host, Dawn, and if you're new here, this podcast is about real life after bladder removal.

[00:00:21] The good, the messy, the funny, and everything in between.

[00:00:25] Before we dive in, I want to gently remind you that I'm not a medical professional. 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 alone.

[00:00:42] I am sharing my lived experience from my own urostomy journey, and also from my husband Alex's neo bladder journey. Because bladder free living comes in many forms from leak disasters to travel hacks, from emotional hurdles to unexpected [00:01:00] victories.

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

[00:01:08] In today's episode, we're going to be discussing the part of the bladder removal people do not talk about enough.

[00:01:16] The physical recovery gets attention, the surgery, the supplies, and sometimes even the how-tos, but the mental and emotional side of this, is where things get hard.

[00:01:28] And for a lot of people, that part is incredibly lonely.

[00:01:34] That was my experience. I did not have the support I needed, and it made everything harder than it had to be.

[00:01:41] Everything changes at once. Your body is different, your routines are gone. Your sense of control feels like it disappears overnight. And then you

were sent home with instructions sort of, but not with understanding. No one is walking you through what this actually [00:02:00] feels like or is supposed to feel like.

[00:02:02] No one is sitting with you in the moments where your mind starts racing, you are just in it, figuring it out as you go, and then your mind gets loud, louder than you expect. You're thinking about everything. Is the pouch secure? Is there a smell? What if something leaks?

[00:02:21] What if something goes wrong and I'm not ready? You check. You adjust. You check again. You start planning everything. Where are the bathrooms? Do I have supplies? What is the backup plan?

[00:02:34] And when you do not feel supported, every unknown feels bigger because there is no one there to say this is normal.

[00:02:43] So your brain fills the gaps and it usually fills them with the worst case scenarios.

[00:02:48] And underneath all of that, there is grief, not just for the bladder but for your life that was before this, the ease, [00:03:00] the normalcy for some.

[00:03:02] The way your body used to feel without you thinking about it all the time, except for, in my case, when I was thinking about it all the time, but the hard part is, you know you made the right decision and still grieve what you lost. The ease, the somewhat normalcy, the way your body used to feel without you thinking about it all the time. And the hard part is you can know that you made the right decision and still grieve your loss. Both can exist at the same time, but a lot of that grief happens quietly because the outside world moves on faster than you do.

[00:03:42] People think you're better. They expect you to be okay, and you're still processing everything. Grief feels heavier when you feel like you're carrying it alone.

[00:03:53] And then there's the part that no one really prepares you for, which is looking at your body, seeing the pouch, [00:04:00] seeing that weird looking stoma, trying to understand what you're looking at.

[00:04:06] It can all feel so unfamiliar and disconnected, and you start wondering if you look different to other people, if this possibly changes how

you are seen, and it changes how you feel about yourself, and there is no roadmap for that.

[00:04:25] No one really walks you through how to process this emotionally. You are just expected to adjust to a body you do not recognize without being shown how to do that. And that takes time, more time than people think.

[00:04:42] There's also something that needs to be said. Clearly.

[00:04:45] There is a major gap between medical care and real life.

[00:04:52] You are kind of taught how to manage the equipment, but you're not taught how to manage your life. You're not [00:05:00] taught how to handle the anxiety or the grief or the body image shifts. I was not taught how to survive this. I was not taught how to live with it.

[00:05:13] I witnessed something similar with Alex's surgery and he had some support and it was kind of the same, yet it was different.

[00:05:23] The gap where a lot of people struggle is the medical side, which gives you one or two pointers on how to take care of the stoma, how to change your pouch systems, but they aren't there to show you how to walk back into a world with this creative plumbing system.

[00:05:42] There is a phase that comes after the initial shock where you are functioning and you're doing what you're supposed to do.

[00:05:51] You're sort of managing things.

[00:05:53] But internally you are struggling... hard.

[00:05:59] This is where it gets [00:06:00] quiet.

[00:06:01] You stop talking about it as much. People assume you're fine and you start carrying more of it on your own. Just because you're functioning, does not mean you're okay.

[00:06:14] For me, the shift did not come from something outside of me.

[00:06:18] It came from recognizing something that I had felt before.

[00:06:23] I had been in this place once already, and that was after my hysterectomy many years ago. At the time, I did not understand what was happening. I just knew I felt off, disconnected and not like myself. I was grumpy. I was angry. I would cry at the drop of a hat.

[00:06:44] It was just weird, wasn't me. But this time it hit differently. It took me about three months before I recognized it. I realized I had fallen into that same place again. It was [00:07:00] not just exhaustion or frustration. It was deeper than that.

[00:07:05] It was depression. And as hard as that was to admit, there was also something grounding in it. Because this time I knew what I was looking at, and more importantly, I knew that I had come out of this before. That did not make it easy, and it did not make it go away overnight, but it changed how I saw it. It was no longer something unknown.

[00:07:34] It was something I had already been through, and that gave me a starting point.

[00:07:39] Knowing what it was, did not fix it, but it gave me a direction.

[00:07:45] The first time I went through this, I did not understand why I felt the way I did. I did not have language for it. I did not know what to do with it.

[00:07:55] But this time, I did. And it started with something very simple...

[00:08:00] I stopped expecting myself to feel okay right away. I gave myself some grace. I stopped trying to push past it, pretend it was not there. I let myself acknowledge it, really feel it, and I let myself be okay knowing that I was struggling, that I felt disconnected, that I did not have the energy I thought I should have.

[00:08:30] And instead of fighting that I started working with where I actually was, some days it meant doing very little, getting up, getting through the day and letting that be enough. Other days, it meant doing one small thing that felt manageable. Not everything, just something.

[00:08:53] I stopped looking at what I used to be able to do and started paying attention to what I could do [00:09:00] in... that... moment, and that shift mattered because it took all the pressure off.

[00:09:09] It gave me space to start rebuilding instead of constantly feeling like I was falling short. I also started to recognize patterns, the isolation, the pulling back, the loss of interest.

[00:09:25] And instead of letting it go unchecked, I became more aware of it. Not in a judgmental way, but in a noticing way. Like, okay, this is where I am right now. And once I could see it, I could start to gently shift it.

[00:09:45] Like I said, not all at once, but in small ways. Reaching out when I did not feel like it. Getting outside and going for a short walk, even if it was just for a few minutes, letting myself be [00:10:00] around people, even if I was quiet. None of it felt big in the moment, but it added up and slowly things started to feel a little less heavy, a little less consuming.

[00:10:15] I did not wake up one day and feel completely different, but I started to feel more like myself again. Little by little. And that is really what it came down to. Not forcing myself out of it, but giving myself the space, the awareness, and the patience to move through it.

[00:10:35] And I share this because I know I am not the only one out there who has been there. Maybe you felt it too.

[00:10:42] Maybe you're going through it right now, that place where you are functioning, but you do not feel like yourself.

[00:10:49] Where everything feels heavy. Even the smallest things. Where you start pulling back from people, not because you want to, but because you just don't [00:11:00] have the capacity for anything else. Where nothing really interests you the way it used to and even things that should help, just do not land.

[00:11:12] And you cannot always explain it while you're in it. You just know something's off. And if that is where you are.

[00:11:19] I want to say this in a very real way. This does not mean something is wrong with you. It means you are in something that takes more from you than people usually talk about.

[00:11:32] Sometimes what we go through is not just physical recovery, it is emotional recovery, too. Mental recovery, learning, how to exist in a life that does not feel familiar anymore, and that takes time, more time than most people expect from themselves.

[00:11:51] What helped me was not pushing harder or trying to snap out of it.

[00:11:55] It was recognizing where I actually was. Without judgment.

[00:12:00] It was being honest about the fact that I was not okay in that moment.

[00:12:05] And it was slowly allowing myself to move through it instead of fighting it every day.

[00:12:14] Not all at once, just enough to keep going. One small thing at a time.

[00:12:21] And for me, part of moving through that also meant getting it out of my head instead of holding it all in. There were things I could not sort out internally, but when I wrote them down, they felt a little less heavy. A little more clear.

[00:12:39] That is actually what led me to create my plot twist journal because sometimes you need prompts to help you name what you're feeling when you're in the middle of it.

[00:12:49] So, if you were in that space right now, I want you to know this is not a place you stay stuck in.

[00:12:56] Even if it feels like that right now, even if you feel [00:13:00] disconnected from yourself, even if your energy, your motivation, or your sense of who you are, feels out of reach.

[00:13:10] That version of you is not gone. You are just in a season where you're rebuilding from a different place than you expected. And rebuilding does not look like progress every day. Some days it looks like just getting through the day, but even that is part of it.

[00:13:28] You plan for life to go one way, and then you learn how to live the life that actually shows up.

[00:13:40] Thank you for joining me today on Leaks, Laughs and Life with a Urostomy. I hope this episode gave you a few insights. Reminded you that you are not alone in this journey.

[00:13:51] 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.

[00:13:58] For more [00:14:00] information, tips and tricks or a copy of the show notes, please go to my website@leakslaughslife.com or connect with me on Facebook, Instagram, LinkedIn, or YouTube.

[00:14:13] I would love to hear from you.

[00:14:15] You can also find "Leaks, Laughs and Life with Urostomy: The Handbook" And "My Plot Twist Journal" on Amazon. They're designed to support those who are new to life as a Urostomate, may be preparing for surgery or supporting someone who is.

[00:14:31] Next week, we are diving into Complications, during and after surgery.

[00:14:37] Until then, take care of yourself. Be gentle with your body. And remember, this journey has its share of leaks, plenty of laughs, and a whole lot of life.

[00:14:47] See you next week.