

7. The Other Side of Bladder Removal: Alex's Neobladder Story

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

[00:00:05] Hello and welcome back to Leaks, Laughs, and Life with the Urostomy. The podcast that proves bladder less living, comes with challenges, a surprising amount of comedy, and the chance to find your zest for life again. I'm Dawn, a wife, mother, artist, and a Urostomate and your guide through the ups and downs and occasional, "oh, no" moments of urostomy life.

[00:00:28] Before we dive in, I want to gently remind you that I am not a medical professional. I'm sharing my lived experience from my own urostomy journey and from my husband Alex's Neobladder journey. Because bladder free living comes in many different forms, from leak disasters, to travel hacks, from emotional hurdles to unexpected victories.

[00:00:48] 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.[00:01:00]

[00:01:00] Each episode brings real talk, practical insight, and heartfelt encouragement on everything from surgery prep, and supplies to relationships, self-confidence and reclaiming your joy.

[00:01:11] You're not alone in this. Thank you for being here. It tells me you showed up on purpose and that means more than you know.

[00:01:19] Today's episode is a little different. You've heard of my urostomy story, but bladder free living comes in more than one form, and the man sitting across from me chose a different path. I thought it would only be fitting that my husband, Alex, should be my first guest. And in this episode we'll be discussing his neobladder journey, the good, the difficult, and the funny things that happened along the way.

[00:01:42] Welcome.

[00:01:43] **Alex:** Hello.

[00:01:44] **Dawn:** It's good to have you on the show today.

[00:01:46] **Alex:** This is fun.

[00:01:48] **Dawn:** All right, let's jump right in, shall we?

[00:01:50] Before we talk about what life looks now, let's talk a little bit about how your journey began. Will you share with us how you discovered, what led you to [00:02:00] having a radical cystectomy starting in July of 2022?

[00:02:05] **Alex:** Okay, so a little background. I've been blessed with good health most of my life. Very rarely getting flu things like that. So, when I feel a little different or not feeling well. Was, okay, this is, this isn't right. We lived in Arizona at the time. I worked construction out in temperatures at 115 degrees or higher, so I noticed my urine was a darker color.

[00:02:41] Another little background tidbit. I'm colorblind. So, to me that just meant I was dehydrated. I drank a bunch of water and that helped with the color. It went away. Fast forward maybe six, eight [00:03:00] months, and then my urine was dark again. So, I called in my color girl to, "Hey, look at this. What do you think?" And she's like, "that is blood!"

[00:03:13] You're going to the doctor, which I love. Doctors.

[00:03:16] **Dawn:** No, you don't.

[00:03:17] **Alex:** Not.

[00:03:19] So, I reluctantly went because I knew it was, it was something scary.

[00:03:26] Went into the doctor. They said it could be anything from an infection or maybe just some urinary tract issues that could cause a little bleeding. But long story short, I needed to see a urologist.

[00:03:43] So, I went to see a urologist. He gave me the background and said, typically this is a sign of cancer to some degree or another. On occasion it's not. I was floored. I don't, don't get sick. [00:04:00] So the big C word was, was scary.

[00:04:04] We had to do a scope. To go in and look inside my bladder, uh, won't go into that fun detail that was not bueno but necessary.

[00:04:16] And doctor did not exactly have great bedside manner. He put the scope in and immediately, "oh, look at that right there. That's a tumor. You have cancer. Pretty bad. You need surgery and then your life's gonna change."

[00:04:33] I didn't have insurance, so he said I needed to go through some steps to take care of that.

[00:04:40] Thank goodness we were divinely guided by angels that flocked around us and pointed us in the right direction for that. He said, first step is we have to go in and remove the tumor, and then we will do testing on it. See what [00:05:00] degree it is and make a plan from there.

[00:05:04] We went in about two weeks later and, had another scope done where they removed the tumor cauterized things, brought forth lots of bleeding and lots of issues.

[00:05:18] And then we were sent to cancer specialists. They set up a game plan for us that I had to have chemo. They were very good at telling us what was gonna happen. I mean, they put it all out on the table so we could see what we are up against. I am somebody who likes to know what I'm getting into.

[00:05:46] I immediately started doing my homework. I started looking on the internet, doing things. Of course you get all sorts of medications everybody wants to give you. Fortunately, I stumbled onto a company called BCAN B-C-A-N [00:06:00] for the Bladder Cancer Advocacy Network, and they were, unlike Dawn's situation, a wealth of information.

[00:06:10] I got to do all sorts of homework on what to expect, what this means. And in the meantime, my cancer specialist had told me that the plan was to get the chemo, 12 weeks of that, wait a month, and then I had to have my bladder completely removed.

[00:06:34] She said there's three options for that. There is the urostomy. There is what's called a neobladder and then there is what's called an Indiana pouch. Urostomy has been around forever. Neobladders been around quite a while and has evolved. The Indiana pouch is the newer of the three and isn't [00:07:00] proven to work so well and does have issues. She suggested that was not one of my choices.

[00:07:07] So, back to doing my homework, on Bladder Cancer Advocacy Network, they had a thing where I could reach out and they put me in touch with other people who've had their bladders removed and chose one of the three

diversions. I spoke at length with four different. Patients who had been through the removal of the bladder.

[00:07:38] I spoke to two who had the neobladder, one who had an Indiana pouch and one who had urostomy. It was pretty overwhelming. A lot of information, as one of my bosses says, it was like drinking from a fire hose.

[00:08:00] Very confusing, emotional. I'm a very active person. Even just around the house, I'm very active.

[00:08:07] Work out in the yard and garden. I hunt, I fish, I hike, do some biking. I didn't think having a pouch on the side of me was going to be my style, so I chose to have a neobladder. I don't know if she's explained it in other podcasts, what a neobladder is, but it's basically where they take part of your intestine, create a little pouch to put the ureters from your kidneys into, to flow into the pouch and then reattach your urethra and basically just kinda redid the plumbing.

[00:08:52] But everything works, kind of like it did before.

[00:08:56] **Dawn:** Creative plumbing.

[00:08:58] **Alex:** Yes. I, I [00:09:00] say kind of like you did before, because we take it for granted how our parts work. They just do. As you probably know, the bladder is a muscle and it squeezes what it needs to squeeze and empties out, and that's how you do your business.

[00:09:17] Well, the new parts, my neobladder is not a muscle. They informed me I would have to be using my muscles, my core muscles, my pelvic muscle and other muscles to help squeeze the pouch and empty it.

[00:09:37] Another fun fact is a bladder has a sphincter on the end of it before it goes into your urethra and it stops or allows the urine to pass through.

[00:09:51] New plumbing doesn't have that. So they said leaks and challenges could be a thing. Some [00:10:00] people it is. Other people it isn't. So I was prepared for that. In the interim, they suggested I worked on getting my core muscles in shape. So being active, that wasn't too big a step. But I started doing yoga. I'd been doing yoga anyway for couple years just to help me keep limber. Working in construction at 60 years old is a challenge in and of itself.

[00:10:28] I started working on my core muscles and then we went through and had the surgery five days before Christmas in 2022. Pretty detailed procedure, and the recovery from, it took a while.

[00:10:50] I had to have a catheter in for four to six weeks. They had said maybe three to start with. Not that I [00:11:00] had issues, but it turned out to be four to five weeks at least, which was a challenge. And then, that was removed and I started the quote unquote new normal.

[00:11:15] I don't know who coined that phrase, but I don't think they were a patient.

[00:11:21] New. Yes, not, not much of the normal side. I don't wanna scare anybody. It was a change, it was a drastic change, but considering the other options. I've always been a hard worker. When there's a job to be done, you hunker down and do the work you gotta do to do the job.

[00:11:43] That's the stance I had going forth with the new normal and what that meant.

[00:11:50] So that's what got me to this situation. And fortunately I had somebody helping me at being a caregiver that [00:12:00] was all in and did her homework and knew a lot about her anatomy and my anatomy. That was way beyond what I knew and helped me to get to and through this new normal. We were three years into it? Three and a half,

[00:12:19] **Dawn:** three, almost four.

[00:12:21] **Alex:** July will be four years into this.

[00:12:24] Very happy to still be here, upright. And quite honestly, it didn't slow me down a lot. There is hope this can be done and this can be done fairly comfortably.

[00:12:40] It didn't slow you down a bit. You still do everything you did plus more before you had the surgery.

[00:12:45] **Dawn:** Did it end up being what you thought it might be like before the surgery?

[00:12:50] What's the difference?

[00:12:51] **Alex:** Yes and no. They tell you what it's like and they tell you about the new normal, but I'm yet to meet a doctor that's [00:13:00] had the new normal. They can tell you what they feel and what their patients have shared with them, but it was a pretty big change.

[00:13:11] There were challenges trying to figure out what it meant not to have accidents, problems, issues, along those lines.

[00:13:23] **Dawn:** What were you most afraid of before the surgery?

[00:13:29] **Alex:** I was afraid it was going to handcuff me, or hobble me if you're in horse terms, to where I had to slow completely down, and to where I could not be active like I am, which would drive me plum crazy if that was the case.

[00:13:47] **Dawn:** Me too!

[00:13:49] **Alex:** Fortunately. The people that I got to pick their brain who had been there before, who had walked the walk, and now we're talking the talk.

[00:14:00] Every one of them in all three diversion methods said if they had it to do again, they would still choose their choice. So there's not a right and a wrong for everybody.

[00:14:14] **Dawn:** Let's talk about the early recovery stages, and you kind of touched on, you did stuff to increase your core muscles and you did try to retrain your bladder. Was it easier than you expected or more difficult to retrain?

[00:14:33] **Alex:** I would have to say, in general, it kinda came natural. I was afraid I was going to have to really, be a contortionist to get things to squeeze, whatever the case may be. And that is to a degree, still the case. But, it wasn't a scary, difficult thing.

[00:14:54] **Dawn:** How did it affect your sleep and nighttime management?

[00:14:59] **Alex:** That was a [00:15:00] challenge in itself.

[00:15:01] I was told right from the get go that leaks are a thing. You would have problems. I was also even told by one of the people who went with my method that they had to self catheter on a regular basis, post surgery to drain their bladder. Of course I thought, nah, that's not gonna be me. I'm not gonna have to worry about that.

[00:15:27] But the learning to squeeze and to void, I guess they call it, wasn't too bad. Nighttimes were the challenge though, because. You have your core and you're clenching or you're learning and doing stuff, when your whole body relaxes, then that's when things got interesting. Wake up in the middle of the night going, oh my goodness. You know[00:16:00]

[00:16:01] **Dawn:** Bolting outta bed!

[00:16:02] **Alex:** Oh gosh! Yes. Depends, we're a thing. Depends are a thing. That scared me that I didn't want to be the little old Depends guy. I am the little old Depends guy. But nighttime was my biggest challenge. It's not any longer. Nighttime is when I had my leaks more often.

[00:16:26] I very rarely had daytime issues. First six, eight months, maybe a year, I wore some sort of protection just to stop daylight occurrences. But nighttime is when I had my challenges.

[00:16:45] **Dawn:** Was there an emotional impact from that part?

[00:16:48] **Alex:** Yeah, I suppose, you revert back to being a little kid, you know?

[00:16:53] You get up and oh my God, I wet the bed. And that, that was hard, you know, having to [00:17:00] wake Dawn up and we had to change the sheets and knock on wood, that hasn't been a thing in a year and a half or better. The new normal has kicked in, gotten routines.

[00:17:13] It was kind of like being back to being a little kid wet in the bed and mentally that was a challenge. But, you know, we got through that with support from my wife and, very fortunate with our doctors at UC Health, they were very good at answering questions, getting information for me, following through and helping with this battle.

[00:17:40] **Dawn:** Do you grieve at all for your old body or did you grieve?

[00:17:45] **Alex:** Yeah, a little bit. I guess to a certain degree. Yeah. There's a new normal and oh my God, this is, this is gonna ruin my life. No, that wasn't the case.

[00:17:56] After I kicked the drama side out, I [00:18:00] realized, okay, well we can do this and we can get on with this, and it's not gonna be, I'm not wearing a big poofy diaper. It's quite doable and really nobody knows unless I

have the conversation. I am usually a very private person, but I chose to kind of chronicle the battle and challenges pretty explicitly on social media and sharing with friends and family.

[00:18:27] And I think that helped me get through it as well. It helped me talk through it, get it out, and realize, okay, I'm not the only one and if I can touch somebody, help somebody that may be going through this, then I'm gonna share my story.

[00:18:48] **Dawn:** Yep. And turns out we've had a friend from high school that also had the same bladder cancer, but he didn't have to have the radical cystectomy.

[00:18:59] **Alex:** Yes. He's, a [00:19:00] friend, we were real close in high school, kinda lived together for years and then went our ways and have touched base. Hadn't talked to each other in 10 years or whatever, and called and talked and he was diagnosed within 30 days of when I was diagnosed, his wasn't stage three to four to where they had to take the bladder.

[00:19:21] They just did, bladder washes. And have continued to do so. His is still an ongoing challenge, but he's whooping it, too.

[00:19:31] **Dawn:** Do you happen to remember the moment that it really hit you when you were settled in and figured out, okay, this is my new normal.

[00:19:43] **Alex:** I can't say I remember a moment. As time went on and I was able to start being active again, start doing stuff around the house. I've been in construction my whole life, so we always have remodel projects. And when I was able to start picking up and doing that again, still worked to a certain degree [00:20:00] with the company that I work for, still continue to work for.

[00:20:04] So, didn't have an aha moment, but it sunk in that, you know, hey, yeah, this is different. This is drastically different, but it's all right. It's gonna be all right.

[00:20:18] **Dawn:** What are some of the pros or cons about having the neo bladder?

[00:20:24] **Alex:** Pro number one for me, and that's what really kinda leaned me towards, the choice I made was it's pretty much the same.

[00:20:35] The plumbing's the same, the equipment is pretty much the same and goes in the same function, and that was important to me. Being able to still have regular bathroom habits to a certain degree. You know, I've found things are easier. It's easier for me to urinate sitting down than standing up, much to my brother's dismay, who used to [00:21:00] always tease me about being a little brother and smaller and weaker and, you know, well, geez, you gotta squat to pee. Well, now I do.

[00:21:10] **Dawn:** Oh, well,

[00:21:13] **Alex:** but it's, it's all right.

[00:21:16] **Dawn:** And cons?

[00:21:18] **Alex:** The cons are, you know, the nighttime routine. Fast forward, up until just before Christmas time, I say October, or so, went in for one of my six months checkups. And they checked to see that I was emptying the bladder completely and I was not.

[00:21:39] So, now I am one of the ones that has to self catheterize. Sometimes, a couple times a day. For the most part I do before I go to bed. That's not fun. Any way, shape, form or manner. Uh, they call it the new normal. Whoever named that [00:22:00] had never had to do this, 'cause they're nothing normal about catheter catheterizing.

[00:22:06] Can't even say that. But now here I am, six months into it and bam, it is the new normal. It's what I do. I guess that fast forwards me to the positive of that is I have been able to sleep much more comfortably. Don't have the leaks . I don't get up in the middle of the night. Very rarely, I still get the signals from my body that something's going on. Sometimes that I might have to go and, you know, have to get up or what have you. But the self catheterizing has made my nighttime routine much more normal.

[00:22:47] **Dawn:** And for the nighttime routine you use? They're not depends, they're like a men's shield?

[00:22:53] **Alex:** They are made by Depend.

[00:22:55] **Dawn:** Oh, they are, Depends. Uhhuh. But they're a shield.

[00:22:57] **Alex:** Yeah. They're a little rather than the whole, they're a pear
[00:23:00] shaped shield that you apply inside your underwear, rather than the
large depends.

[00:23:08] **Dawn:** You don't have to wear the poofy ones.

[00:23:09] **Alex:** Yeah. Did that, you know, I thought well, that's fine. That's,
that's okay.

[00:23:14] I am a warm bodied person at night. I sleep with a sheet most of the
time. Wearing a full-blown Depends with the plastic, Plastic. I was in a little
personal sauna. No bueno. Um, so the, the little Depend that I still use as a
backup. I haven't had to rely on it really in months and months and months,
thank goodness.

[00:23:43] I do have some cloth, what we call pee rags that are maybe an eight
inches by 10, 12 inches that, I kind of helped wrap and it's my first line of
defense. The downside of [00:24:00] what I found is if I'm having a leak,
especially if I'm laying on my back, then it just, if you have, it depends, doesn't
matter because it just runs along the outside of your body and run into the
backside of your body.

[00:24:16] So that has been different. So using, using the little, pee rag, as we
call it, to help wrap things, has helped that. I still do that to this day and it
catches the teeny bit. Because I catheterize now, it gets me through a seven,
eight hour night without an issue.

[00:24:39] **Dawn:** The pee rags were what I used before my surgery because we
went through rolls and rolls of toilet paper and so we ended up using pee rags so
that I didn't have to use all the toilet paper.

[00:24:51] **Alex:** Well, we live on a septic system and yeah. And septic didn't
take it. I was afraid it was gonna plug things up.

[00:24:58] **Dawn:** Okay, so next [00:25:00] question. We both lost our bladders
in different ways. What was it like watching me navigate a urostomy after you
had navigated a neobladder?

[00:25:12] **Alex:** It was very interesting to see. Okay. What if I went that
avenue? How would things be? And like I said before, it reiterated to me there's
no set choice. It's what's best for the individual. I am very happy with the choice

I made. I don't think I would've been comfortable or happy with the choice you made.

[00:25:41] And so it reiterated that, do your homework, know your body, and you can make the choice that's right for you and you can live with it and it will be normal.

[00:25:52] **Dawn:** If you've heard " how I got here" my first episode, I had interstitial cystitis and.

[00:25:59] I was [00:26:00] peeing anywhere between five to 15 minutes all day long, all night long. And so the reason I chose the urostomy pouch was because I didn't wanna have to pee another day in my life. I was done peeing. I just wanted to have a bag where it would drain and I didn't have to deal with it. So that was my choice on choosing the urostomy because I didn't wanna have to deal with the leaks from the neobladder and I didn't wanna have to try to train my bladder and how to go through all that. I just wanted to be done with it.

[00:26:34] He's helped me through my surgery, because his humor got me through a lot of it, and I think between the two of us, the support we've given each other, was amazing understanding where each other was or what was going on.

[00:26:55] **Alex:** Not trying to make choices for the other one, letting the other [00:27:00] figure out what's right for them. What I think is a real takeaway from this is, we all really know our bodies and no two are the same with their routines. And doctors, I don't think, give us enough credit for knowing our bodies, until we're forced to do something like this.

[00:27:24] And. What choice you make, more often than not, I'm yet to meet anybody that says, "no, I'd do it differently.

[00:27:32] **Dawn:** Right.

[00:27:33] **Alex:** So knowing your body and having faith in yourself and doing it.

[00:27:40] **Dawn:** Who do you think is a good candidate for the Neobladder?

[00:27:45] **Alex:** I think people who are more active. Um, you know, I still, am really active in doing things around the [00:28:00] house, around the yard,

crawling in crawl spaces, doing stuff like that where. I was terrified of having a pouch. I saw that as a recipe for disaster with me.

[00:28:14] Getting up and down on ladders, crawling around in the yard, weeding the yard, bending over. Trying to keep things as original equipment as possible, was important to me.

[00:28:28] **Dawn:** Is there anything you wish you would've known before surgery that you didn't?

[00:28:35] **Alex:** That's a hard one. We were so blessed with, I mean, you get something like this thrown at you, your head's spinning, your world's spinning, your going, oh my God, I can't do this. Why me? All of those things. Don't be afraid to ask questions. Inform yourself. We're in a [00:29:00] day and age where you can push a few buttons.

[00:29:02] Ask. I don't know if I'd ask ai. I am not a real fan of it for that. But, you can get some homework and find some things out to where you can make your choices and be happy with them.

[00:29:16] **Dawn:** If you could sit across from the version of yourself the week before surgery, what would you say to him?

[00:29:25] It's not gonna be easy. It's something you can do, which I've always been a positive person. I'm a glass is half full, actually, not a glass is half full, I'm a glass refillable person. Yeah. But if I could sit back and say, you know, there's gonna be some bumps, you might even go off the road. You might get stuck and have to get pulled outta the ditch.

[00:29:53] I was floored eight months ago when they told me I had to self [00:30:00] catheterize. I was angry. I didn't sign on for this. And, and then I looked back and it's like, no, wait, these guys told me. Mm-hmm. That, you know, we have to self catheterize.

[00:30:11] Well, that's something when you've never had to do it or you don't know. Yeah. What's that mean? I was upset when that had to happen, and still to this day, sometimes get frustrated with it, but it is what it is. It's not comfortable, but life isn't easy. I was always told that as a kid. So you cinch up your belt and you get on with it and you make it easier yourself.

[00:30:42] Are you proud of him?

[00:30:44] **Alex:** Absolutely.

[00:30:46] **Dawn:** I'm proud of you, too.

[00:30:47] **Alex:** I am proud of us being the team. I wasn't the caregiver that she was by any means. I'm not as patient as she is on doing that. And I think by nature [00:31:00] men aren't as good caregivers. Not that it's a woman's way, but it's just been part of woman's evolution forever, that they take more naturally to it.

[00:31:11] That was one of the harder things for me is being the caregiver, but then to be able to look back and say, wait a minute, this is nothing compared to what she went through for me and how she stood by me.

[00:31:26] **Dawn:** Thank you. Make me cry. You have anything else you want to add?

[00:31:32] **Alex:** You know, through Dawn, if you're coming up to this and it's gonna happen, I would love to do what I had the opportunity to do.

[00:31:43] And if you have questions, you can reach out through her and we could make arrangements to where we could have a talk. I talked to people that were in the state of Colorado. I talked to people that were around the country, and they [00:32:00] allowed me to make an informed choice, and realize it's all right and you too will be all right.

[00:32:13] **Dawn:** Yeah, and if you need to, you can email me @leakslaughslife.com. If you go to the website, there's a block where you can email me and type in there what you want to say, and we'll get back to you as soon as possible.

[00:32:31] Thank you for being on the podcast. You shared some really good insights, and thanks for being my first guest.

[00:32:39] **Alex:** Mm-hmm. I'm very proud of what you're doing. Thank you. You're being selfless and thinking of others and don't know why I would think that's surprising 'cause I've known that my whole life with you. But it's another thing that I wasn't super comfortable with having to do this, but [00:33:00] I would be happy to help anybody make a decision or things along those lines.

[00:33:08] **Dawn:** Alright. Thank you.

[00:33:09] **Alex:** Mm-hmm.

[00:33:10] **Dawn:** Love you.

[00:33:11] **Alex:** Love you.

[00:33:12]

[00:33:12] **Dawn:** Thank you so much for listening to 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.

[00:33:23] 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.

[00:33:29] For more information, tips and tricks or a copy of the show notes, please go to my website@leakslaughslife.com.

[00:33:40] Next week we're talking about something a lot of people wonder about after surgery, exercise. What is actually safe? What should you avoid, and how do you get back to moving your body without accidentally giving yourself a hernia or launching a dumbbell across the room?

[00:33:59] I'll be walking through [00:34:00] the real life do's and don'ts of exercising with a urostomy. Along with some of the practical tips to help you rebuild strength, protect your core, and feel more confident about getting back to the activities you enjoy. If you've been wondering whether you can work out again, this episode is definitely for you.

[00:34:17] Until then, take care of yourself. Be gentle with your body, and remember, laughter is life's best medicine. Leaks happen, laugh often, and I will see you next week.