📍 Hello and welcome back to Leaks, Laughs, and Life with a Urostomy. I'm Dawn, a wife, mother, artist, and a Urostomate. On this podcast, I will be sharing what life with the urostomy is really like. We will explore day-to-day survival, practical tips, intimacy, identity issues, leaks, and the truths no one warned you about. This is a space for honest conversation, connection, and the moments that make you laugh when life throws the unexpected at you.

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

Today, we're discussing all the things I wish someone would've told me about this lifestyle before my bladder was evicted. The little things, the big surprises, the stuff no one warned me about. Whether you're facing bladder removal yourself, caring for someone who is, or just curious about life after bladder surgery, this episode's for you.

Let's start with the things that surprised me the most.

First, the logistics. I thought I understood what living with a urostomy would be like. After all, I read the pamphlets. I watched a couple of YouTube videos. And I watched my hubby go through the neobladder surgery and thought, man, I got this piece of cake.

Well, not really piece of cake. I knew it was gonna be kind of tricky, but I thought, yeah, not a problem. Nope. Nothing really prepares you for the reality of figuring out pouch systems, adhesives and leaks while you're learning your body's new rhythms, and more than anything, the emotional impact. I didn't realize how much grief would sneak in, not grief for my old bladder because she was no longer welcome.

But grief was more about losing a part of me. The physical and the emotional identity. Your body changes in ways you didn't sign up for, and it takes time to accept that as part of your story, and it's hard.

So let's talk about the physical surprises.

Recovery is not just about the pain and the stitches. It's also about the stamina and adjusting to your new routines.

The odd quirks your body now has the sleeping differently, learning to carry extra supplies, realizing how your day-to-day movements feel completely different, and recognizing what some of those little twinges and tingling feelings mean. There are so many questions I had that I didn't know I should have asked before surgery.

I've had many surgeries prior to the eviction of my bladder, but this was on a whole nother level. When I began researching, I really couldn’t find much information on the internet about what to ask or what I needed to know before I met with the surgeon. For that matter, I couldn’t find anything about what life was going to be like with a urostomy. I watched Alex with his neobladder surgery, and it was difficult. I guess I figured mine would be like his…I really had no clue what to expect.

I’d like to share a list of things I wish I would've known to ask. Okay, here we go:

Where's the best placement for the stoma?

It makes a huge difference in the clothes you will be able to wear and the pouching systems that you'll have access to. Make sure you discuss and mark out exactly where your surgeon thinks it is going to be placed.

Do I have a say where the stoma is placed?

I know the answer is yes to this one because the placement of mine was due to a hernia. What I didn't know was that it was going to be situated way below where the stomas are normally located. An inch or an inch and a half makes a huge difference when it comes to the pouching systems. Because there are different lengths and styles.

I had to go with a smaller, shorter pouch because the longer ones came down to the middle of my thigh, it was not comfortable.

How long will recovery really take?

Everyone is different, but it took a lot longer than I expected, like months longer.

What are the restrictions immediately after surgery?
And then after three months, after six months after a year, the rest of my life?

For the first three months, you can't do anything. There's no lifting, there's no driving, there's no bending, there's no pulling, no exercising. Oh, and ladies, there's no vacuuming. None.
And then gradually as you move through, you get to bring new activities on board.

I was taking two to three naps a day. But that was ok, my body needed the rest. DON'T push it, because if you do, you will pay dearly for it in the pain department later.

My sixth month, I was still moving very slowly. But! I was only taking one nap a day and was able to be up and out of bed for longer periods of time. I began driving again and that was a bit uncomfortable, but so nice to get out of the house! Still had to have someone come grocery shopping with me, I couldn't lift the bags, 5 lbs. felt like I was lifting 50.

It was finally at the 8th month mark that I regained my energy and was able to get through the day without a nap.

Different people will have different recovery times. I think it is safe to say that your energy will not return as quickly as you wanted it to, but realize, this was a MAJOR surgery. Your body will need plenty of time to recuperate. Just be patient with yourself and be gentle with your body.

Then there where the questions: how will I be able to do the housework, driving, lifting, exercising?

You will not be able to do housework. No lifting, no exercising, except for walking. Walking is the only exercise you will be able to do for several months.

The one restriction that I didn't know about until just before my surgery was about how much weight I would be able to lift, for the rest of my life…15-20 lbs. PERIOD. I was fine with that, didn't really think it through…I can't lift a tire to change it, suitcases are generally around 25 lbs.

All I can lift now is 15 lbs. Anymore and it's too much pain, and I do not want another hernia!
I know with the neo bladder there is no weight restrictions after you have fully recovered.
So something to think about..

I still would not change what I did…I am happy with my choice!

Will I need assistance after surgery? And for how long?

Yes, you will need assistance and you will need a lot of it.
You will feel totally exhausted for quite a while…getting out of bed and going for a short walk…I don't mean around the block, more like down the driveway and back, is a feat in and of itself.
Time wise, I would say at least four to six weeks is helpful to have someone make your meals, do your laundry, clean your house, do your grocery shopping, etc.
I know it sounds like a long time, but in the scope of things…it's a bleep in time.

What are some of the complications that can happen?

The doctors always go over brief statements of the possible complications. They do this with every surgery. I guess my brain was elsewhere that day because I don’t remember any of the details. I recommend when they do discuss them with you, have someone with you to hear what they are saying, because you won’t hear it all
and if you have questions, ask, please ask. This is your life. You need to know.

I don’t want to scare you, but I did mention in the first podcast, I will not sugarcoat anything, and I am going to be honest with what happened to me…

So, let me briefly tell you what happened to me. My complications began at the very beginning of my surgery, not because of my surgeon, she was amazing. But mine were due to a massive amount of scar tissue surrounding my intestines. The surgery was supposed to be done robotically and take about 2 hours.

Mine took 2 ½ hours longer than expected because she had to do it old school, not robotics.

Afterwards, my intestines did not want to cooperate and move things through. They almost had to do surgery again. Instead, they put a drain tube down my throat to remove the bile that wasn't moving through the proper channels.

You can't leave the hospital until you can, well, poop, which usually happens on day 3 and then you can go home the next day.

My stay turned into eight. On the sixth day, finally, things began to move…my husband came into the room, and I was in the bathroom…I was so excited that things were finally moving, and my nurse laughed so hard when I yelled out, "Alex, I pooped my pants!" Not many people would be too happy about doing that, but the reason I was so happy is that it meant I got to finally eat something and would be going home soon…and finally, on day eight I was released from the hospital.

What foods are best avoided during the first few months.

Your diet will be based solely on how your recovery is going. If where your intestines were joined together have decide to play nice with each other, you will be on your way to recovery!

Soft foods for the first week or so, then as your body is able to tolerate firmer foods, you can slowly introduce them into your diet.
My intestines were not cooperating. There was apparently a family feud going on down there…Which meant I was only able to eat soft foods, no meat, no raw fruits, no raw veggies, no rice.

I could have veggies if they were cooked to oblivion, not a fan of that. So, I ate mashed potatoes, sweet potatoes, pudding, cream of rice and ice cream.

It took about four weeks for me to tolerate hamburger, or chicken. And about six weeks before I could eat fruit. Longer for veggies or salad.

The next question was, what is the daily routine going to look like for me after surgery in three months, six months, or you know, and after a year?

This question is one I really had no idea what to expect.

For the first three months, I was resting/sleeping and walking as much as I had the energy for, which was not much.

Showering was a challenge, because I just didn’t have the energy, and I dreaded trying to change my pouch. It was frustrating for the first few times.

It took everything I had to get in that shower…I showered every three days and changed my pouch every time I did.

After three months, I was able to get a routine down and it was easier, especially after I found a pouch that was my stoma’s “soul mate.” That’s a whole different topic!

At six months, things were really beginning to settle down. I had a routine that finally clicked, and my body was beginning to feel stronger.

At eight months, I had found my “new normal” routine, and I really was feeling like my old self again…only better. Life was good again!

You need to know, it's going to basically be at your own pace, and don’t push it…

How long will I be off work?

It depends on what you do. Desk jobs, you may be able to go back after six-eight weeks. It just really depends on your healing journey. If you do something more physical, you may have eight to 10 weeks before you can go back. You'll need to check with your surgeon and your doctors for that.

Around eight weeks, I went back for a couple of hours a day to begin with and only two days a week.

How will I feel, really feel… for the first three months? In six months, in a year?

and when I say feel, I mean emotionally, not physically, because we all know it will be a struggle physically. I was not prepared for the mental and the emotional part, and it's taken me probably four months to get through that struggle.

Everything changes, your body, your routine, you may feel like you are spiraling because you have no control over anything right now.

Expect emotional shifts. Oh boy. Grief, relief, anxiety, and pride can all hit at once.

Things are frustrating, pouch changes, unexpected leaks, not being able to get up out of bed and move without pain, you struggle to do most things that were so very easy for you not so long ago.

Time and patience will be your friends.
It is going to take a lot of both.

How will I know what supplies to order and how to order supplies, and what do they even look like and what are they called?

I had NO CLUE…NONE.

I called an was able to get a few samples before my surgery, which I never tried…because I had no idea what to do. They were all way too long for my body and came down to the middle of my thigh…not comfortable!

Your stoma/ostomy nurse will be able to help you with some of this information.

You will get some supplies from the hospital, and they may or may not be working for you.

How will I know what pouch or system works best for me?

Good question.
And, unfortunately, that one is one that no one will be able to answer for you because this is all so new, and things change during that first month and second month.

It is a lot of trial and error, because no two bodies are alike. Everyone has different likes and dislikes when it comes to pouches, and styles.

For instance, your stoma size, it will change. It will either shrink or get bigger. You just never know, and your abdomen will change shape. So, there's a lot that goes into determining what you will be using and what pouching system will work best for you.

Really, it's all a mystery.
You will have to become a detective and figure out the clues as to what your body likes and what feels good.

Trust me, you will know when it happens! And it will…just give it time! Try a bunch of different pouches, get sample from the manufacturers…

In my next episode, I will be sharing information about pouches, styles and their manufacturers, and little things to watch out for, stay tuned for that! Some suggestions to get you through this frustrating period of exploration and accidents. One, give yourself grace. Learning your body's new rhythm is a marathon, not a sprint. Some days will feel easy and others will not. You can't learn it all at once.

Practice patience with supplies. Don't be discouraged if the first few pouch systems don't work perfectly. It's normal to try a few before finding your match, and of course, you are going to have lots of leaks in the beginning. It's part of the learning process.

Humor is essential. You will have those leaks, the spills and awkward moments. Laughing doesn't mean you're not taking it seriously. It just helps you to reset your perspective and realize that this too shall pass.

Is there anyone I can call with questions?

Your Stoma/ostomy nurse will guide you for the for couple of weeks, but after that, you may need to seek real life guidance. Medical teams are amazing, but they haven't lived it. Support groups and people who've walked this path are invaluable.

Talking about it helps normalize the experience.

Wardrobe adjustments, the things that no one tells you about, to make life more comfortable. I was told, eh, there's no need to change a wardrobe. So not true. I will do a whole podcast on this coming up soon.

You have a different body, different surgeon, different suggestions, but looking back, I wish I'd known adaptation, is ongoing. This is not just a few weeks of recovery. It's a whole new way of living.

Even the gross or awkward moments will eventually become part of the rhythm of life. Many of these suggestions you will need to speak to your surgeon and get the answers about what's right for you.

I also wish I had known how resilient I really am. I have learned to get creative when I'm faced with a challenge and I love how humor sneaks in in the middle of chaos.

Learning to live with a urostomy is teaching me patience, self-compassion, and to celebrate the small victories that feel enormous when your body's plumbing has been creatively re-plumed.

The part no one really prepares you for is how much growth comes out of surviving something so strange, so life altering, and so humbling.

📍Thank you so much for listening to Leaks Laughs and Life with Urostomy. I hope this episode gave you a few insights, maybe a laugh or two, and reminded you that you are not alone in this journey.

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.
You'll find more information, tips and tricks, and the show notes on my website@leakslaughslife.com.

In the next episode, we'll get practical and dive into the different styles of urostomy bags, the different manufacturers, and how you go about ordering, how to choose what works best for you, and tips for getting started.

Until then, my friend, take care of yourself. Be gentle with your body and remember.

Laughter is life's best medicine.