

Urostomy Survival Kits

[00:00:00] Oops. Moments happen, but today we are turning panic into, "I've got this," with simple everyday and travel urostomy toolkits that make life a whole lot easier. I

[00:00:13] Hello and welcome back to Leaks, laughs, and Life with Urostomy.

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

[00:00:29] Before we dive in, I want to gently remind you that I am 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, to learn, and to feel a little less alone.

[00:00:47] I'm sharing my lived experience from my own urostomy journey. And also from my husband, Alex's Neobladder journey. Because bladder free living comes in many forms from leaked disasters to [00:01:00] travel hacks, from emotional hurdles to unexpected victories.

[00:01:05] Thank you for being here. It tells me you showed up on purpose, and that means more than you know.

[00:01:11] Today we are talking about something that every single one of us will experience at some point, those "Oops" moments. You know, the ones, the unexpected leak that the timing could not possibly be worse.

[00:01:26] The tiny bathroom with a zero counter space where you're standing there thinking, "Ugh, crap, this is happening again?"

[00:01:35] So, before we get into today's episode, I want to share one of those moments because if you know, you know.

[00:01:44] One morning I was a bit overconfident and did not carry my kit with me into work. It was close by, but it was not with me. Picture this, I'm at work, everything's going great.

[00:01:59] I was feeling [00:02:00] overly confident about my pouch change that morning. "Wow, this is getting easier. I'm rocking my pouch changes."

[00:02:07] I get into work, I'm there about two hours, and then my stoma decides, "ego check."

[00:02:16] I felt it. That little, "ah, crap" trickle and then it wasn't a trickle. Suddenly my brain went from calm and cool and collected to full on problem solving mode.

[00:02:29] I headed for the bathroom, trying to act normal. I make it into the bathroom and realize, of course, my supplies are in my backpack, out in my car.

[00:02:41] My brain starts freaking out.

[00:02:43] "Great. Now what am I gonna do?" Thank goodness I had grabbed my phone without even thinking. So, I texted my boss, "HELP! I'm having a bit of a situation. Will you please do me a huge favor and get my keys out of my purse and grab my backpack [00:03:00] out of the backseat of my car?"

[00:03:02] And in that moment. You realize two things very quickly. One, this is happening whether you're ready or not. And two, being prepared would've made this situation a whole lot easier.

[00:03:16] And that right there is exactly why we are going to talk about every day and travel urostomy toolkits. Because when you are prepared, those "oops" moments go from overwhelming to manageable really fast.

[00:03:34] When I first started this journey after my bladder eviction, I did not fully understand how important it would be to have supplies with me at all times.

[00:03:46] I thought it, I would just, you know, run a quick errand and be fine. And of course, those are the exact moments when something happens. It does not take long to realize that being prepared is not about expecting the worst. It's about giving yourself [00:04:00] peace of mind so that you can actually go out and live your life.

[00:04:04] So let's start with your everyday toolkit. This is your grab and go. Take it with you everywhere. Little bag of confidence. It's to take with you on errands, appointments, lunch with friends, all the normal day-to-day things.

[00:04:18] Your everyday kit does not need to be huge. It can fit in a little bag inside your purse or a backpack, but it does need to be thoughtful.

[00:04:27] I like to keep at least one extra urostomy pouch. A few barrier strips. We will also need, if you use barrier rings, you'll need to put those in there. You'll need a wafer that is precut and ready to go. A few disposable bags, add in some of the little cloth-like napkin towels that I talk about in my book. They're extremely handy.

[00:04:51] You'll need some adhesive remover wipes, and skin protectant wipes. Having all of these will cover a lot of [00:05:00] situations.

[00:05:00] A small mirror is something I did not think about at first, but it is a game changer, especially in those less than ideal bathroom setups.

[00:05:08] A small package of baby wipes is a must, and I always recommend having an extra change of underwear just in case in your backpack or bigger bag that stays in the car or if you carry it with you, a change of clothes in the beginning can be a godsend in some situations. And don't forget the socks. Maybe an extra pair of shoes because yes, I have had a steady stream running down my leg and right into my shoe, and it was not comfortable walking around in.

[00:05:42] Although it did make a great catch basin, it didn't flood out everywhere else. So we've had its

[00:05:48] This is where you level things up a bit. This is good for road trips, for flights, overnight stays, or anytime you're going to be away from home for a longer period of time. Take everything from [00:06:00] your everyday kit and build upon it.

[00:06:02] More supplies, more backups. Think two or three full changes instead of one, just in case. If you're going for more days, then please take what is necessary for you with a few extras.

[00:06:16] Make sure your wafers are precut for traveling so you don't have to deal with the whole scissor issue. Going through TSA, some will allow the rounded tip scissors. Some do not.

[00:06:27] Also add in your night drainage bag and tubing if you use one, any leg bags, if you use those, bring extra clothing, like a full outfit, not just underwear. Trust me on this one, just in case. If you use seal rings, the

barrier rings or paste to make sure those are packed as well. And extra barrier strips can be really helpful in moments where you just have sprung a little leak. They do help stop that.

[00:06:58] A waterproof bag is also [00:07:00] great for keeping everything protected and contained. So if something gets wet, then you can put it all in there. If you are traveling further, having a copy of your prescription is not a bad idea.

[00:07:12] This is your, we are not getting stranded. We are going to be prepared kit.

[00:07:17] If you are flying, check with your airline to see if they allow an extra medical supply bag in addition to your two carry-ons. Some airlines do, some airlines don't.

[00:07:28] And a word of caution. Always carry your supplies on the plane with you.

[00:07:36] Do not put them in your checked luggage.

[00:07:40] They won't do you any good if you are in California and they are in Paris. It's not easy to get extra supplies when you're away from home.

[00:07:50] I know it can feel like a lot at first, but once you have it set up, it becomes second nature. You grab your bag and go, just like you would a purse or your keys. [00:08:00] Guys, just a little travel bag works too. Just remember to restock whatever you use out of them so you don't get stranded the next time.

[00:08:10] Now let's talk about the mindset piece for a minute, because this matters just as much as the supplies do.

[00:08:16] "Oops!" Moments are going to happen. It's just part of life with a urostomy. But being prepared changes how you experience them.

[00:08:25] Instead of panic, you move into action. Instead of stress, you have a plan. You may still have a moment where you think, "seriously, right now, couldn't you find a better time to do this?" But then you handle it and you move on, and that right there is what builds confidence over time.

[00:08:44] I want to share something with you that I came across just a couple of days ago, and I think it is extremely clever. I have been trying to get information but have not heard back from them as of yet. It's called the *Change Frame* from En Route Living. They are in the [00:09:00] UK, and this is one of those things where you look at it and think, "okay, this solves a very real challenge."

[00:09:07] It is essentially a hands-free system designed for Ostomates, but it can be used in our case as well.

[00:09:14] It includes a carrying case for all of the supplies, a belt and a bag holder that attaches to the belt and hangs below your stoma to catch any leakage.

[00:09:25] So if you are in a situation where there's no clean surface or no surface at all. You have a place for your supplies and your disposal bag all at your fingertips. It's brilliant.

[00:09:37] Think about those tiny bathroom stalls, the road trips, outdoor adventures, or anywhere you're standing there trying to figure out where to put things.

[00:09:46] This gives you a setup that moves with you. You are not relying on the environment around you. It's designed for ostomates in general, but I can absolutely see how Urostomates would benefit from this as well.

Especially when you're out and about or [00:10:00] traveling, because not all bathrooms are created equal, and having tools like this available is a game changer.

[00:10:08] I looked on their website and I'm not sure if it's \$120 or it's 120 pounds. I'm assuming it's 120 pounds, but when I find out more information, I will definitely share that on my Facebook and my Instagram account.

[00:10:23] Thank you for joining me today on Leaks, Laughs and Life with Urostomy.

[00:10:27] I hope this episode gave you a few insights, maybe a laugh, and reminded you that you're not alone in this journey.

[00:10:34] Before we wrap up,

[00:10:35] I want to remind you that both my new books *Leaks, Laughs and Life with Urostomy: The Handbook* and *My Plot Twist Journal*, are both now available on Amazon, I will post the links in the show notes.

[00:10:49] I would really love to hear from you. If you have had an oops moment yourself, a lesson you've learned, or something you wish you would've known sooner, please send it my way. I would love to start sharing listener [00:11:00] stories in upcoming episodes. Because the more we talk about this, the more we realize we are not alone in it.

[00:11:07] If you found this information helpful, please subscribe so you don't miss an episode and share it with someone who might need to hear it.

[00:11:15] For more information, tips and tricks or a copy of the show notes, please go to my website@leakslaughslife.com. You can also email me from there if you have a question or want to share a story with me.

[00:11:27] I would love to hear from you.

[00:11:30] In next week's episode, this is a special one. I will be celebrating one year of life, as a Urostomate, and what a journey it's been. I will share what I've learned, what surprised me, and how far this journey has taken me, and also I have an update on possibly a new addition into the information area.

[00:11:51] Very exciting. I'm excited about it.

[00:11:56] Until then, take a deep breath, pack your [00:12:00] toolkit, you've got this. And remember, this journey has its share of leaks, plenty of laughs, and a whole lot of life.

[00:12:08] Goodbye for now.

Links:

Book: *Leaks, Laughs & Life with a Urostomy: The Handbook* ...Amazon Link: <https://a.co/d/0aFJXcHX>

Journal: *My Plot Twist Journal* ...Amazon Link: <https://a.co/d/0drdioYl>

Website: <https://leakslaughslife.com>

Podcast: *Leaks, Laughs & Life with a Urostomy Podcast*: <https://leakslaughslife.com/podcast-%26-show-notes-1>

En Route Living Website for Change Frame bag:

<https://enrouteliving.com/products/change-frame-carry-case-with-belt-dry-bag>