

Nighttime Bags = Sleep, Glorious Sleep!

[00:00:00] There are parts of living with the urostomy that no one really talks about. For instance, leg bags and nighttime drainage. So, let's talk about what that actually feels like.

[00:00:12] Hello, and welcome back to Leaks, Laughs, and Life with Urostomy. I'm your host, Dawn, and if you're new here, this podcast is about real life after bladder removal, the good, the messy, the funny, and everything in between.

[00:00:27] 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 to create a safe space, to laugh, learn, and feel a little less alone.

[00:00:45] I am sharing my lived experience from my own urostomy journey and also from my husband's neobladder journey because living bladder free comes in many forms, from leak disasters, to travel hacks, from [00:01:00] emotional hurdles to unexpected victories.

[00:01:03] Thank you for being here. It tells me you showed up on purpose, and that means more than you know.

[00:01:10] Today we are talking about something that can completely affect how you feel the next day, even though it happens at night, nighttime bags. Then there's the leg bags, tubing, straps, and all the things that nobody really walks you through in a way that feels real when you're first figuring this out.

[00:01:28] If you've ever, in bed thinking. "Did I hook this upright? Is this going to leak? Why does this feel so uncomfortable?" You are definitely not alone.

[00:01:39] I remember those nights, the overthinking, the checking, the trying to get comfortable while also feeling like you're attached to something that has a mind of its own.

[00:01:49] This is one of those parts of life with the urostomy that sounds simple on the surface. But when you're living it, it becomes about sleep, confidence, and honestly just [00:02:00] trying to be able to relax.

[00:02:02] So, today I want to walk through this with you in a really real way. What the difference is between your daytime setup and your nighttime setup. What to expect and some of the little things that can make a big difference when it comes to actually getting some rest.

[00:02:20] During the day, most of us are using our pouch, and that becomes part of our normal, pretty quickly. It is designed to be discreet. It moves with you, and over time you figure out how to live your life without constantly thinking about it.

[00:02:35] Now, leg bags are a whole different story. For me, they're more of a backup plan than an everyday go-to, and I'm just going to say it. Leg bags are kind of my nemesis. Okay. Not kind of, they are.

[00:02:51] I swear. Whoever designed them has never actually had to wear one.

[00:02:56] Those elastic bands can dig into your legs. They feel awkward [00:03:00] and bulky, and once they start filling up, you really feel the weight of it. It is not exactly the most comfortable or confidence boosting setup.

[00:03:10] So no, they are not all peaches and cream.

[00:03:13] But with that said, they do have their place. When you need extra storage or when you're traveling, or when you're in a situation where frequent emptying is not easy, they can be really helpful. It is one of those things where you may not love it, you may hate it, but you're glad that you have it when you need it.

[00:03:35] And when it comes to nighttime bags, not all setups are created equal, and this is where you really start to figure out what works for your body and your sleep patterns.

[00:03:48] There are two main types that I have had experience with and they're very different from each other. One is the Bard, BARD, nighttime bag. This one has a [00:04:00] thicker round tube. And it's connected to your pouch with a separate connector that usually needs to be taped, so it doesn't come out, not the part that actually attaches to your bag, that doesn't get taped every night. It's just the connector that attaches to the hose.

[00:04:17] It works, but it can be a bit clunky. And the tubing, at least in my experience, has a tendency to kink. And when that happens, you can end up with a very full pouch, which is not exactly what you want to wake up to in the middle of the night, feeling this really full pouch on your body.

[00:04:37] Then there is the Coloplast, that's C-O-L-O-P-L-A-S-T, Coloplast nighttime bag. And for me, this one has been a much better fit. It was a game changer for me.

[00:04:51] It is sleeker. The hose is much thinner, and it is a non-kinking hose. It is also much longer than the Bard bag hose, which [00:05:00] makes a big difference. I tend to hang it down at the bottom of my bed, off the footboard, and I can run the hose down between my legs instead of off to the side.

[00:05:10] And that one change alone makes it so much easier for me to sleep comfortably. I can roll from one side to the other without feeling like I'm dragging tubing with me or getting tangled up. And it takes away that feeling like you're in a wrestling match every time you want to move. Which is honestly a huge win.

[00:05:27] If you are five foot seven or taller, running it down between your legs may not be an option because it's not that long, but you can still run it off to the side of the bed and it's a lot easier to maneuver than the Bard hose is.

[00:05:44] Now a quick heads up on this one because this is something that's not always explained when you go to order it.

[00:05:50] When you order the Coloplast nighttime bag through a medical supply company, a lot of times it does not come with the handle that you actually need [00:06:00] to hang it. They send you the bag, but not the hanger. So, you must order that separately. And it can be tricky to find on their websites because it is not always labeled in a super obvious way.

[00:06:13] What you're looking for is called the Conveen bag hanger for drainage bags. That's C-O-N-V-E-E-N bag hanger for drainage bags. The reference number on the package is 5 0 7 0 and it's a two-piece green handle that connects to the Coloplast bag. Once you have it, it makes setup so much easier. But getting to that point can take a little bit of digging if you do not know what you're looking for.

[00:06:43] So I wanted to save you that frustration, uh, because I did experience that, twice. Trying to find it is not easy.

[00:06:54] Another little trick I learned with the Coloplast system is something I check every single night without even [00:07:00] thinking about it. It has become a part of my bedtime routine, before I fully settle in. I always check to make sure that that plug is on the right side.

[00:07:08] It's a quick visual cue that everything's aligned, and my pouch is lying flat against my body just the way it should be.

[00:07:15] Positioning is one of the biggest things that makes a difference at night. Gravity is your best friend here, you want your nighttime bag lower than your body, so everything can flow easily.

[00:07:25] For me, that usually means hanging the bag off the foot of the bed, or if I'm sitting up in bed, it hangs off the side of the bed.

[00:07:33] And here's a little tip that came from experience. I like to keep a small trash can or container underneath the bag with the bag like hanging in it as a backup. Because things can and do happen.

[00:07:51] I had a night where the valve got bumped open and oh my gosh, it made such a big mess. One of the moments you do not forget, and ever [00:08:00] since I've always had something underneath the bag just in case, especially if I'm in a hotel or at somebody else's house. It would be rather embarrassing if something happened.

[00:08:12] So just a little reminder. It's a simple thing, but it gives you that extra layer of protection and peace of mind, so you could actually relax and go to sleep.

[00:08:22] The tubing can be a bit of an adventure. If it gets kinked or twisted, you're going to notice. So take a minute to lay it out in a way that feels natural before you settle in.

[00:08:34] It can save you from having to adjust things later when you're half asleep.

[00:08:38] Let's talk about that feeling, being aware of it. The hose. In the beginning, it can feel like you are never going to forget it's there. Every movement, every shift, you're thinking about the tubing, the bag, the setup. Is it going to kink? Is it going to leak? And over time, that does ease, your [00:09:00] body and your mind both adjust and eventually it just becomes a part of your new normal.

[00:09:05] Another thing that can happen at night and honestly feel a little bit alarming if you're not expecting it. Is what I call the ballooning effect. This is not something you usually notice in the middle of the night.

[00:09:16] It's more of a morning surprise!

[00:09:19] You wake up and look down and your nighttime bag looks like it's about to explode.

[00:09:24] It is filled with air, not just fluid, and it can feel a little shocking the first time you see it.

[00:09:30] It's just gas. Your small intestine naturally creates gas as a part of digestion, and with the urostomy, your stoma and ileal conduit are made from that small intestine. So it's still doing what it's designed to do. It's just in a different role now.

[00:09:47] So, what you eat during the day can absolutely affect what happens overnight.

[00:09:52] If you are noticing more of that ballooning effect, it might be worth taking a look at the foods that tend to create more gas, things like [00:10:00] beans, broccoli, cauliflower, cabbage, and some starches can all contribute. And this does not mean you can never eat these foods, but if you are having a stretch of mornings where you're waking up to that overfilled air heavy bag, try easing back on them for a bit and see how your body responds.

[00:10:18] It really is a bit of trial and error. You start to notice patterns and over time you learn what your body handles well and what might be better earlier in the day or in smaller amounts. And just like everything else with this, once you understand what is happening, it goes from feeling scary to something you can manage.

[00:10:38] Leak anxiety is real. I think almost everyone goes through that phase where you're not quite trusting the system yet. And what helped me was having a setup that after a period of time, I felt confident in using it and sticking with it.

[00:10:56] Confidence does not happen overnight, but it builds [00:11:00] night by night. You start to relax a little more. You stop checking as often. You start sleeping more deeply and that is a really big milestone.

[00:11:12] One thing I like to share is what I call either discoveries or "learned the hard way" tips. The things that you figure out through experience, those little discoveries, like keeping a backup set up nearby, especially at night. It just gives you a peace of mind knowing that there's something easy to grab in the middle of the night in case your bag happens to pop a little hole, which I've had happen.

[00:11:39] Just have something accessible and create a simple routine that you follow each evening so you're not trying to remember the steps when you're tired.

[00:11:48] And in the morning, always rinse and sanitize your nighttime bag. And also same thing with your leg bags and hoses. Rinse first [00:12:00] with warm water and drain it into the toilet, and then sanitize with either there's a Hollister M9 sanitizer or you can use one part vinegar to three parts, water to sanitize.

[00:12:14] Close the drain spouts and to fill the bags, use a bottle. I use the M9 sanitizer bottle that comes with the M9 sanitizer, because it has a small tip and it will fit in the hose to sanitize those. The bags don't need to be completely full. You can swish the sanitizer around in them and then release the sanitizer into the toilet and rinse again with cold water, hang it in the shower with a drain spout open and the hose hanging down to dry.

[00:12:48] And try to do this every day because otherwise the bag is going to stink and it's going to grow mold and it's more of, um, what's the word I'm [00:13:00] looking for? It's more of a hazard for UTIs. So please make sure you rinse and sanitize your bags.

[00:13:10] If you are traveling, take a few minutes when you get to your room to set up your whole routine just like you would at home. It makes a huge difference.

[00:13:21] And most importantly, give yourself some grace. This is something you are learning. It is okay if it feels awkward, or frustrating at times, and there will be leaks. Just don't let them ruin your night.

[00:13:34] And remember, it's all a part of this journey. I know this part of life is not something anyone really prepares you for, but it does get easier. You find your rhythm, you figure out what works for you, and little by little you get your nights back. And when you start sleeping better, everything feels better.

[00:13:55] While we're talking about all of this, I want to share something that fits right into this conversation. [00:14:00] A lot of what I'm sharing here today came from figuring things out the hard way. The nights of trial and error, the stress of not knowing if I was doing things right and slowly building confidence over time.

[00:14:13] And that is really why I created my book, *Leaks, Laughs, and Life with a Urostomy: The Handbook*. It is everything I wish someone would've handed to me in those early days. Real life explanation, practical tips, and the kind of honest details you do not get told in a clinical setting.

[00:14:32] I also created *My Plot Twist Journal* because this journey is not just physical. There are emotional shifts too. Moments where you are adjusting, processing, rebuilding confidence and learning how to see your story differently.

[00:14:49] This journal is a space for all of that. I just wanted to put those out there in case you're in a place where you're looking for something that helps you feel a little more [00:15:00] grounded or a little less alone in the process. They're both available on Amazon and I will put the links in the show notes located on my website at leakslaughslife.com.

[00:15:12] Before we wrap up today, I want to pause for a moment and say something really important.

[00:15:19] I would love to hear from you. You can find me on Facebook, Instagram and YouTube. At Leaks, Laughs, and Life with Urostomy.

[00:15:29] Come say hi. Please connect and be a part of this growing community. I truly want this to feel like a space where we can all show up just as we are. A place to share our experiences with no judgment, just support and comradery.

[00:15:44] And I have something special coming up.

[00:15:46] In a future episode, I would love to share real wins from people living with urostomy or a neobladder. And when I say wins, I mean all of them. Big wins, small wins, funny wins, messy [00:16:00] wins. The ones that made you proud, and even the ones that surprised you and caught you off guard, and the ones that really made you laugh.

[00:16:10] I have had many of those. If you have an "I did it" moment, an "aha" moment or something you've figured out since surgery that made life a little easier or a little lighter. I would love for you to share it with me or others so that it can help others in their journey as well. You can send your story to Dawn, D-A-W-N@leakslaughslife.com or post on any of my socials, and you might hear it featured on an upcoming episode.

[00:16:43] Let's take a moment to celebrate these wins together because they matter more than we sometimes realize, and they can mean a lot to other people.

[00:16:53] Thank you for joining me today on Leaks, Laughs and Life with a Urostomy.

[00:16:56] I hope this episode gave you a few insights, [00:17:00] maybe a laugh, and reminded you that you're not alone in this journey.

[00:17:04] 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.

[00:17:10] For more information, tips and tricks, or a copy of the show notes. Please go to my website at leakslaughslife.com.

[00:17:22] Next week we are diving into the topic of mental health check-in and why this is important.

[00:17:28] Anxiety, grief, and body image are part of the process, and we need a safe place to process all the feels.

[00:17:37] Until then, please take care of yourself. Be gentle with your body.

[00:17:42] And remember, this journey has its share of leaks. Plenty of laughs, and a whole lot of life. Bye for now.

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/0drdioYI>

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