

The UTI Danger Nobody Warned Me About

[00:00:00]

[00:00:00] Hello and welcome back to Leaks, Laughs, and Life with a Urostomy. The podcast that proves bladderless living comes with challenges, a surprising amount of comedy, and the chance to find your zest for life Again.

[00:00:13] I'm Dawn, a wife, a mother, an artist, a Urostomate, and your guide through the ups and downs and occasional, "oh, no!" Moments of urostomy life.

[00:00:25] 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 forms from leak disasters, to travel hacks, from emotional hurdles to unexpected victories.

[00:00:45] 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.

[00:00:56] Each episode brings real talk, practical insight, [00:01:00] and a heartfelt encouragement on everything from surgery, prep, and supplies to relationships, self-confidence and reclaiming your joy. You're not alone in this.

[00:01:10] Thank you for being here. It tells me you showed up on purpose, and that means more than you know.

[00:01:16] Today we will be discussing the UTI Danger that nobody warned me about. This episode isn't here to scare you. It's here to inform you and prepare you, because the more knowledge you have, the better off you will be in the long run. I did not see my first UTI urinary tract infection coming.

[00:01:37] I thought a UTI would feel like they used to before surgery. Annoying but manageable. And I was feeling very proud of myself, at the time. My routine was beginning to feel solid. My pouch changes were mostly calm, and life was starting to feel somewhat normal again.

[00:01:52] And then I woke up one morning with 102.5 fever, horrible chills, and body aches.

[00:01:59] Now my son [00:02:00] at the time had strep throat, so I was writing it off as though I had strep throat. But, my throat wasn't sore, and then I had a deep, awful feeling that something was very wrong.

[00:02:13] A few hours later, I was sitting in the emergency room.

[00:02:16] I was extremely fortunate. The ER physician's assistant actually knew what a urostomy was, and better yet, knew how to deal with my urostomy.

[00:02:27] That is not common, especially for a small town hospital. He moved quickly and ordered blood work and a CT scan. And that was the moment I realized how unprepared and uninformed I was.

[00:02:40] It was then that I learned just how dangerous a UTI can be after a radical cystectomy.

[00:02:47] He was amazing and he saved my life. Thank you, Matt. A few more hours and I would've gone septic. And we all know that's not somewhere anyone wants to go.

[00:02:58] If you have a urostomy and you [00:03:00] haven't dealt with a UTI yet, congratulations, but also buckle up.

[00:03:06] In this episode, we're going to talk about what A UTI looks like now, how to recognize early signs, how to advocate for proper testing and what prevention looks like in real life.

[00:03:19] There will be practical tips and hard earned lessons because sometimes the only thing worse than a UTI is not knowing what you're dealing with.

[00:03:30] If you've already dealt with one, you understand. If you are worried about getting one, that concern is reasonable. The goal here is awareness and preparation. If you have a urostomy, UTIs are going to come up, not might. Not maybe. They will.

[00:03:47] Keep in mind, UTIs are not always obvious with a urinary diversion.

[00:03:52] Symptoms can be subtle, vague, or as easy to dismiss as dehydration or stress. [00:04:00] This is what makes them so risky. The anatomy is different, so the presentation is different. Like I said, I don't want to scare you, but I do want you to be informed and for you to stand up for yourself if you think you have one.

[00:04:14] What a UTI looks like now because it is different. These are some of the common symptoms that should not be ignored with the urostomy or a neobladder:

[00:04:23] Cloudy urine, that is more than typical mucus cloudiness

[00:04:27] Strong odor from your urine that is noticeably different from your new normal urine

[00:04:34] Fever or chills above 101 degrees, if it's higher, please go to the ER immediately, not the urgent care, the ER

[00:04:43] If you have flank, back or right-side pain

[00:04:48] If you have extreme fatigue or brain fog

[00:04:52] If you have flu-like symptoms, but it doesn't feel quite like the flu

[00:04:58] If there's increased mucus beyond your [00:05:00] usual baseline of mucus

[00:05:02] All these symptoms can escalate very quickly.

[00:05:06] What starts as something feels off can turn serious very fast.

[00:05:11] The question, is this normal or should I call someone?

[00:05:15] If you're asking that question and you have any of the symptoms I just discussed, call your provider. Ask to speak with someone familiar with Urostomies or Neobladders, because not every provider understands how serious UTIs can be with a urinary diversion. If something feels wrong, do not ignore it. Follow your intuition. You know your body better than anyone. Don't second guess it. Trust your gut. Better to be safe than sorry.

[00:05:43] UTIs are more common with a urostomy because the urinary system has been rerouted.

[00:05:49] Urine drains continuously through a stoma to an external pouch. That open system allows more opportunity for bacteria to enter compared to a bladder that fills and [00:06:00] empties. The conduit is made from small intestine, intestinal tissues produce mucus and naturally contain bacteria.

[00:06:10] Mucus can trap bacteria and slow the flow, which increases the risk of infection. Even when everything is functioning properly, the environment is simply more bacteria friendly.

[00:06:22] External appliances also matter. Pouches, night drainage bags, leg bags, tubing, and all the connectors that all come in contact with urine and are reused. These require regular cleaning, sanitation, and replacement because even with good care, bacteria can still find a way in.

[00:06:43] Night drainage helps prevent overfilling, but it increases tubing and exposure time. Keep the bag below stoma level, prevent kinks and clean and sanitize equipment after every use.

[00:06:59] [00:07:00] Dehydration also plays a major role. Concentrated urine allows bacteria to thrive.

[00:07:05] Thicker mucus slows drainage. Illness, heat, and travel, increase fluid needs. Hydration is not optional with a urostomy. It's necessary.

[00:07:17] When it comes to testing issues. Getting a clean urine sample is important.

[00:07:23] Standard urine testing does not apply the same way after a urostomy as it did to when you had a bladder.

[00:07:31] A sample from the pouch reflects what is in the pouch, not necessarily what's happening in the urinary tract. The proper way to grab a sample from the stoma is done with a stoma catheter. The stoma is cleaned and a sterile catheter is gently inserted a short distance into the conduit to collect fresh urine.

[00:07:50] This doesn't hurt because there are no nerve endings in the stoma itself. This method provides a more accurate culture and helps target the correct [00:08:00] antibiotic. Many clinics are unfamiliar with this process.

[00:08:04] That is usually a training gap, not neglect. If needed, calmly explain that urine should be collected via stoma catheter rather than from the pouch. You can say, "I have a urostomy, and samples need to be collected directly from the stoma. Not the usual clean catch method." If staff are unsure, request a urology consult.

[00:08:27] Practical preparation helps. Carry a note from your urologist stating how to collect urine properly, keep instructions saved on your phone or bring support with you. Sometimes they are better advocates for us than we are.

[00:08:43] You will need to wear a two piece pouch for this method.

[00:08:45] If you have a one piece pouch, you'll have to change your pouch directly after the catheter draw.

[00:08:50] I highly recommend changing your pouch after any procedure that is done in a non-sterile environment anyway.

[00:08:58] Be aware that many clinics [00:09:00] and ERs rarely see Urostomies and they treat them like Foley catheters or like bladders, and only know about using standard urine collection protocols that don't apply to urostomies. Know that that isn't usually malice. It's lack of training. That's why self-advocacy matters.

[00:09:19] Talk to them and tell them what needs to be done.

[00:09:22] When it comes to antibiotics, are they a friend? Frenemy? Or a necessary tool?

[00:09:27] Recurrent UTIs can feel like a cycle. Symptoms appear, antibiotics help, and weeks later it happens again. Over time, concern about resistance becomes real. Broad spectrum antibiotics given before cultural results can contribute to resistant bacteria.

[00:09:45] When antibiotics are necessary, complete the full course. Stopping early can leave behind bacteria that are harder to treat next time. Proper cultures matter. Targeted treatment reduces unnecessary exposure and improves [00:10:00] outcomes. The goal is not avoiding antibiotics at all cost, the goal is using them wisely.

[00:10:06] Prevention became less theoretical and more practical after my second infection. There is no perfect system, but patterns matter.

[00:10:14] Hydration consistently makes a difference. When I drink enough water urine stays lighter and mucus flows better. When I do not, everything thickens and drainage slows.

[00:10:25] Emptying your pouch at one third to one half full. Keeps the flow moving. And reduces pressure. Stagnation increases risk.

[00:10:37] Night drainage has been both a lifesaver and occasionally a suspect, in my case. I love sleeping through the night without worrying about overfilling, but longer tubing means more places for urine and bacteria to hang out. I've learned that keeping the bag below stoma level, checking for kinks to make sure it's not backing up, and cleaning and sanitizing the [00:11:00] equipment after every use makes a real difference.

[00:11:03] I don't aim for perfection. I aim for good enough and consistent, which turns out to be far more realistic.

[00:11:11] Another lesson in balance is keeping the pouch changing and supply area clean.

[00:11:15] Early on, it's easy to think that if clean is good, extra clean must be better. Clean does not mean surgically clean. I've found that a regular wipe down of the counters and table in my changing area, regular pouch changes, routine cleaning and sanitizing of my night bags and leg bags are enough.

[00:11:35] UTIs still happen sometimes, and when they do, it's not because I failed at hygiene. It's because urostomies don't come with guarantees.

[00:11:46] Then there's the mucus. Yes. It's so gross. But it's part of life now, and it's completely normal. It looks dramatic, but it does not automatically mean infection. Staying hydrated helps more [00:12:00] than anything else, and on days when mucus gets thicker, I pay closer attention to how things are draining rather than immediately assuming the worst.

[00:12:08] With my functional nutrition background, I tend to question, "why?" "Why does it look like that?" Quite often!

[00:12:17] What I found was that there was more mucus when I ate starchy foods like potatoes, breads, pancakes, chips, tortillas, or even dairy products like sour cream or yogurt.

[00:12:32] Now I tend to drink a lot more water when I eat those types of food. And the mucus is still there, but it's less sticky.

[00:12:40] Supplements and dietary suggestions are where things get a little bit more individualized. I've heard people swear by, and I tend to agree about drinking cranberry juice. Now, I tend to drink the ocean spray zero because it has no sugar. Yes, it's a little more tart, but I'd rather have that than the sugar.[00:13:00]

[00:13:00] Taking good probiotics and supplements like D-mannose, in particular, also help. I happened to find a supplement that has both cranberry and D-mannose, and I love it, and I swear by it.

[00:13:13] Please check with your care team to make sure that it's right for your body if you choose to take it.

[00:13:20] Another tip I learned, and this is a very important one, when you have a diagnostic test done, for instance a loop-o-gram or an ultrasound, if you have a two piece pouch, wear it. And when the procedure is performed, you can put the, top of the pouch on and then take it off and then put it back on. But when you get home, please make sure you change your pouch immediately. The procedures themselves are not done in a hundred percent sterile environment. And I can tell you there are plenty of germs floating around in those rooms.

[00:13:56] If you're wearing a one piece, you'll have to apply a new pouch anyway, just make [00:14:00] sure you're wiping down the counters with sanitizer wipes before laying out your supplies and applying.

[00:14:05] I made the mistake of not changing my pouch the second I got home. I waited until the next day and I paid for it dearly afterwards. The UTI I spoke about before, this is where it came from.

[00:14:19] For me, prevention isn't about control. It's about awareness, flexibility and giving myself the best odds possible. While accepting that sometimes UTIs still sneak through the cracks.

[00:14:31] Recurrent UTIs, when it becomes a pattern, there's a point where UTIs stop feeling like an unfortunate event and start feeling more like a pattern. For me, that was when the anxiety kicked in. Before the symptoms even fully show up, when there's a strange smell, a dip in energy or a vague sense of something's off, it automatically sends my brain straight to, "oh crap, here we go again." And recurrent [00:15:00] UTIs don't just affect the body. They can

wear you down emotionally, especially if you're stressing over whether or not it is one or not.

[00:15:07] One of the hardest parts of feeling dismissed by providers, even when you know something isn't right. When the UTIs keep coming back, it's easy to be labeled as anxious, complicated, or just someone who gets infections a lot. Add a urostomy into the mix, and suddenly you're explaining your anatomy from scratch while trying to convince someone that your symptoms matter. That combination being sick and not fully believed, can be more draining than the infections themselves.

[00:15:37] This is where tracking infections become less about being organized. And more about protecting sanity. Writing down dates, symptoms, culture, results, antibiotics, and how long the relief lasted, helps me to see patterns that were easy to miss in the moment.

[00:15:56] It also gave me concrete facts to bring into [00:16:00] appointments, which shifted conversations from vague frustration to documented reality. Having a record made it harder for my experience to be brushed aside.

[00:16:10] When UTIs keep recurring, it's often a sign that it's time to widen the circle of care. Urology can look at anatomy, drainage, and structural issues.

[00:16:21] While infectious disease specialists can help untangle resistant bacteria, recurring strains or treatment strategies that go beyond the usual rotation of antibiotics. Needing a referral isn't a failure or an escalation, it's an appropriate response to a very complex situation.

[00:16:40] Knowing when to push for deeper testing takes time to learn. Repeated infections, worsening symptoms, short-lived relief from antibiotics or cultures that keep showing the same bacteria, are all signs that guessing isn't enough anymore. Ask for imaging, repeat cultures collected properly, or specialist [00:17:00] input, isn't being difficult, it's being realistic. Living with a urostomy already means adapting to a body that works differently. Managing recurrent UTIs sometimes mean pushing for care that reflects that reality. Recurrent UTIs are hard. Not just medically, but emotionally, and you deserve care that treats both.

[00:17:23] Looking back, I would tell myself to expect UTIs to be part of this journey. I would also tell myself to trust my observations and request proper testing sooner.

[00:17:34] For anyone newly diverted, you can live fully with a urostomy, even with occasional infections.

[00:17:41] Some days are frustrating, some are exhausting, but knowledge changes the experience.

[00:17:46] Most importantly, don't underestimate your own voice. Your experience matters. Your patterns matter, your questions and insistence on proper care matter. The more you track, observe and advocate, [00:18:00] the more you reclaim control over a system that once felt unpredictable.

[00:18:05] Every step of knowledge you gain chips away at uncertainty. And every time you advocate for yourself, you build confidence in the reality that you are capable, informed, and entirely in charge of your urostomy journey.

[00:18:20] Thank you so much for listening to Leaks, Laughs and Life with a Urostomy. I hope this episode gave you a few insights and reminded you that you're not alone in this journey.

[00:18:30] 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. For more information, tips and tricks, or a copy of show notes, please go to my website@leakslaughslife.com.

[00:18:46] Next week's episode is a special one. You're going to hear from the other half of this bladder free household.

[00:18:53] I will be sitting down with my husband, Alex, to talk about his neobladder journey, what his recovery was like, [00:19:00] what surprised him most, and what life looks like now from his perspective. It is honest and unfiltered. And if you or someone you love is facing bladder removal and weighing options, you will not want to miss this conversation.

[00:19:14] Until then, take care of yourself. Be gentle with your body and remember.

[00:19:19] Laughter is life's best medicine.

[00:19:22] Leaks happen, laugh often, and I'll see you next week.