

## 18. Mind the Gap: What Doctors Don't Always See

[00:00:00] Living with a urostomy changes more than your body. It changes how you move through the medical system, too. This week, we're talking about the gap between what doctors know clinically and what patients learn by living with it every single day. From self-advocacy and journaling to those awkward moments where you realize you know more about your appliance than the person asking questions.

[00:00:22] This is a conversation about bridging that gap, one honest conversation at a time.

[00:00:28] Welcome to Leaks, Laughs, and Life with a Urostomy. I'm Dawn. And before we dive in, just a quick reminder that I am not a medical professional. I am simply someone living this life, sharing my own experiences and what I've learned along the way, and the things I wish someone had told me sooner.

[00:00:47] Always use what I share as a conversation starter, not medical advice.

[00:00:53] So today, I want to talk about something I've noticed over this past year of living with a urostomy, and I'm guessing many [00:01:00] of you have noticed it, too. There's a definite gap between what doctors know medically and what patients learn by actually living this every single day.

[00:01:10] That's not criticism, it's just a reality. Doctors are trained in surgery, anatomy, complications, healing timelines, scans, labs, and procedures. They know how to create a urostomy, how to monitor one clinically, and what warning signs to watch for medically, and that knowledge matters deeply and saves lives.

[00:01:32] But living with a urostomy outside the hospital is its own kind of education. It's the middle-of-the-night leaks, the skin irritation that builds slowly over time, the products that work beautifully for one person, the products that work beautifully for one person and fail miserably for another, the stress of traveling, the anxiety of even leaving the house, anxiety of going to an appointment. The way [00:02:00] hydration, heat, movement, sleep, and even emotions can affect how everything functions.

[00:02:05] Those are things you don't fully understand from a textbook or a chart. And honestly, I think that's where many patients start feeling unseen, not because providers don't care, but because they are often seeing a clinical snapshot while we are living the full reality. One thing I've realized is that many of us become accidental experts in our own care.

[00:02:28] We learn through repetition, mistakes, problem-solving, frustration, and plain old survival. We start noticing patterns. We know what our normal feels like for our own body. We know when something changes, even if the labs haven't caught up to it yet. And sometimes that creates this strange di-

[00:02:52] And sometimes that creates this strange disconnect where you walk into an appointment thinking, "I know something is off," but [00:03:00] everything on paper says things are technically fine. Both perspectives can be true at the same time, but it can leave patients feeling like they're trying to explain an entire life experience in a 10-minute appointment while someone types into a computer and asks, "Anything else?"

[00:03:17] And why is it that the second they ask that question, your brain completely empties? You walk in with a whole mental list, and suddenly you can't even remember your own name sitting there on that table with crinkly paper.

[00:03:31] That's honestly the part of why journaling has become so important for me, not in a dear diary kind of way, but in a practical, everyday way.

[00:03:41] When you live with a urostomy, there are so many little details that become important over time. Changes in output, skin irritation, leaks, fatigue, foods that affect you differently, products that stop working, patterns that come and go, and trying to remember all of that during a [00:04:00] rushed appointment, or remember it.

[00:04:06] Trying to remember all of that, and especially during a rushed appointment, is almost impossible. Writing things down helps bridge that gap. It helps you notice patterns, explains changes more clearly, and helps you to remember the questions you wanted to ask before your brain completely shuts down.

[00:04:28] That's one of the reasons I created "My Plot Twist Journal". I wanted a place to track the real life side of living with a urostomy, the pieces that often don't fit neatly into medical appointments, but still affect daily life in huge ways.

[00:04:42] And I had a moment recently at my one-year follow-up appointment with my surgeon that really drove this entire conversation home for me.

[00:04:52] I gifted a copy of my book, "Leaks, Laughs, and Life with a Urostomy: The Handbook", to my surgeon, who as a matter of fact, actually [00:05:00] encouraged me to create the podcast and write the book. And I honestly wasn't expecting much from it. I was just excited to give it to her, and I just wanted to share with her, so she could see the patient side of things a little more clearly from our side.

[00:05:17] She started flipping through the random pages and reading bits and pieces to herself, and after a few moments she stopped and said, "Oh, I didn't know that." Turned a few more pages, and later she said, "Well, I didn't know that either." Then eventually she looked at me and said, "Hmm, interesting perspective. Guess I need to read your book. Looks like I will be learning a few things."

[00:05:41] And honestly, I loved that moment, not because I knew something she didn't, but it because, but because it was an honest response, and it reminded me that lived experience adds another layer to the conversation.

[00:05:55] Patients carry information too, different information, real life [00:06:00] information, and I think sometimes we forget that sharing those experiences can help providers too. Not in a confrontational way, not in a gotcha kind of way, just in an honest human way. Because no matter how skilled someone is medically, they still don't go home and live in our bodies afterwards.

[00:06:20] And that's why I think self-advocacy matters so much. Not aggressively, not combatively, just honest, clear and calm interactions. Learning how to explain what's normal for your body, what has changed, what concerns you, and what daily life actually looks like outside the hospital walls. And at the end of the day, the goal isn't patient versus doctors.

[00:06:45] Far from it. The best care happens when clinical knowledge and lived experience work together instead of competing with each other, and that's how the gap gets smaller.

[00:06:57] Before we wrap up today's episode, I just want [00:07:00] to remind you that you do not need to become a medical professional to advocate for yourself.

[00:07:04] You just need to stay connected to your own body and trust the fact that your lived experience matters, too. If you'd like more support and resources, you can find links to my book, *Leaks, Laughs, and Life with a Urostomy: The Handbook*, and also to my *Plot Twist* journal. All of my podcast episodes are on my website, plus much, much more, at [leakslaughslife.com](http://leakslaughslife.com).

[00:07:32] You can also connect with me on social media. On YouTube and Facebook, it's *Leaks, Laughs, and Life with a Urostomy*, and on Instagram, it's [leakslaughslifeurostomy](https://www.instagram.com/leakslaughslifeurostomy). I share more real-life moments, conversations, and the occasional reminder that none of us really know what we're doing in the beginning, and we all learn the same way: by experience.

[00:07:54] Thank you so much for being here with me today, and wherever you are in your [00:08:00] journey, I hope this reminds you that your experience has value, even when it doesn't show up on a certificate. I'll see you next time. Bye.