

## **Episode 175: Mike wears an ostomy pouch**

How would you handle it if you ended up having a medical condition that suddenly made you different from everyone else, in the most embarrassing way possible?

That's what happened to Mike.

Today you'll hear about when Mike got the news from his doctor – sorry, you won't be able to poop the normal way any more. From now on, for the rest of your life, you'll use a bag, actually called a pouch, and you're gonna poop directly from your stomach into that.

And when Mike got that news, he was just a kid – not even a teenager yet.

So today, Mike's gonna tell us what that was like, and how he handled it, and what it's like today, as an adult with an ostomy. I asked Mike all the questions that normally you'd never be comfortable asking someone in this situation.

This conversation with Mike is so real. That's what we do here – real life. You'll hear it all, because Mike is open to talking about everything. And you know what else he is? He's happy and he loves life. Because he wants people to know – if you get the diagnosis he got, it's not the end of the world.

### **Scott**

I have so many questions for you and the funny thing is these are not questions that you would normally ask someone about cause they're so personal. But you are so great about wanting to kind of get all this information out there. I really appreciate that.

### **Mike**

I really appreciate the opportunity to get it out there because it's not something that is easy to bring up in conversation, but it's something that I think needs to be talked about and people in this situation need to hear.

### **Scott**

So what exactly is ulcerative colitis?

### **Mike**

Ulcerative colitis is an autoimmune disorder that when a person's body thinks it's under attack, it kind of ramps everything up and your body creates a huge amount of white blood cells in an attempt to combat invaders that aren't actually there but your body thinks it does, and what that ends out doing is it does a lot of damage to your own organs. So for me, ulcerative colitis is when your colon is affected by this disease. What happened in my case is the disease really got the better of me and it totally decimated my colon back when I was a kid in 1990 and had to have the entire colon removed.

### **Scott**

And how old were you when you got that diagnosis?

### **Mike**

I was 10 years old. Yeah. So I was born in 1979 and my first symptoms started late 1989, early 1990.

**Scott**

And what were the symptoms? What did you first notice?

**Mike**

The first thing - and I'm never going to forget this as long as I live - was blood, a lot of blood. I was a very happy, healthy, and normal kid in all respects. Then, one day, I was sitting in the bathroom on the toilet and whenever I stood up, I noticed bright, red dots all over the floor, all over my underpants, all over the toilet seat, and the entire toilet was just bright red. I remember asking my mom to come and have a look and it was actually the look on my mom's face that was the first thing that made me realize that I was probably in a bit of trouble.

**Scott**

That has to be the scariest thing, not just for you to see that "obviously, something's wrong", but for her to see that.

**Mike**

You know how easy it is to kind of be tough about something but, as soon as you see that caring look on your mom's face, it was rough.

**Scott**

Yeah. Obviously, for something like that, you go to the doctor or maybe you went to the emergency room or something. But how did they try to treat it?

**Mike**

I got hooked up with a gastroenterologist pretty quickly and it was pretty uncomfortable. There were a lot of glove tests, a lot of smears, and looking in microscopes. I still remember the doctor very kindly letting both my mom and I have a peek in the microscope and you could actually see the white blood cells that were just going bananas. They were really just all over the place. The treatment itself started with, like most things, medication and quite a lot of it. So the immediate medication that I was put on was a steroid called prednisone, which is actually a pretty common drug. But, as a young guy, they put me on maximum amounts of prednisone immediately, along with a few other helper medications, and I can tell you actually that prednisone was maybe a little rougher than the disease at the time. It ballooned my body up. It was really rough on my eyes and my joints. So everything got really rough really fast. Even though the blood issue did lessen quite a bit with that first round of medication, it unfortunately wasn't able to kind of dam up the breaking river there. So it still required surgery after a couple of months of attempts.

**Scott**

As you were going through this process, you were still just a young kid. Did you ever have thoughts that you might not live through this?

**Mike**

Well, honestly, it didn't take too long in my youth before I really thought I was going to be done. I still have a very strong memory of the hospital child psychologist coming to sit down with my mother and myself, of course, and she tried to tell my mom that it would be in everyone's best interest if they started talking about end of life, and my mom— again, you feel like you can kind of fight anything on your own. Even as a kid, you always have this kind of maybe unrealistic but

super strong feeling of youth and “I'm going to get through this”, but it was as soon as medical professionals were telling my mom that it's time to start looking at the possibility that I might not be able to make it through this because - and I should point out too - I was losing up to a pint of blood a day at the worst of times here. It was so severe. I was getting blood transfusions and it still wasn't holding up. So even as rough as stuff like that was, both my mom and I did have to contemplate the idea that I just might not make it through that.

**Scott**

What a thing - even for an adult but for a young kid - to already be contemplating mortality. You just don't think about that as a kid.

**Mike**

It was hard to explain to my friends.

**Scott**

So the option was surgery and it was a permanent ileostomy. Can you describe what is that procedure?

**Mike**

Absolutely. I should say, at first, there was a brief hope that other experimental medications would maybe do some good for me. So for a very brief time, they left in just the tail end of my colon while removing the majority of it. What that meant was I still had a rectum and it still had the same traditional exit point and the other end of it came to the foreground of my abdomen on the left-hand side of my abdomen. So it was just about a one-foot-long piece of intestine that wasn't really connected to anything, that was just left in the hopes that it would heal on its own.

The opposite end where your large intestine, your colon connects to your small intestine, your ileum— because that had been severed, the ileum, the small intestine was brought to the foreground of my abdomen and they do a gentle little cuffing of the end of the intestine and suture it there. That becomes your stoma and, for lack of a better term, your man-made butthole. It's just no longer on your butt but it performs the same function. That was my first day with an ileostomy. Even though that one wasn't permanent at the time, it was not much more than a couple of weeks to maybe a month afterward when the amount of blood that was still coming out of the tail end of the large intestine was still so severe. They decided, “Okay, that's it. We got to get it all out of there.” And that was when I became a permanent ostomate and here I am now, over three decades later.

**Scott**

Safe to say you've survived.

**Mike**

I have.

**Scott**

When you got that permanent surgery, how painful was it when you first woke up?

**Mike**

Well, hospital drugs are great. Even as a kid, they still give you quite a good dose there. But in spite of the medication, it was movement that was near impossible. I can still picture it. When I opened my eyes for the first time and was not really sure what I was going to see post-surgery,

they give you a clear pouch just so doctors and nurses can see exactly what's going on there. Also, post-surgery, this might be more info than some of your listeners might want but everything that comes out of you is almost pure black and green bile. It's just not at all pleasant. So when I first saw this long transparent post-surgical pouch of what looked like liquid death attached to me, it was really shocking. It was really hard to see that. And for the actual physical pain, yeah, again, with those hospital drugs, as long as I was just lying there kind of aghast at the sight of it, but not moving, I was okay. It was the very first time that the nurse tried to sit me up and I had to move around a little bit when the reality of the full abdominal surgery was pretty devastating and then it was a lot of pain for a long time. I walked like a little old man for a lot of my youth.

**Scott**

Did they explain everything to you ahead of time about how your life was going to change because of this?

**Mike**

They didn't explain everything. I think when I look back on it, I had a very caring, very professional doctor who worked at our local children's hospital, and he was really great. But I think it was probably— it was a lot of the nurses, after the fact, who really had a lot more understanding of what life was like with an ostomy, who really armed me with a lot of little survival tips and tricks that have really seen me through these last 30 years. But the doctor himself, I'll be honest, I was pretty perplexed. I think every time he sat down and tried to explain the science and the mechanics behind it, the practicality of what life was going to be like was kind of out the door. It really just seemed like really strange magic to me that this guy was trying to explain and not even having an actual ostomy pouch to show me.

I'll be honest. As a kid, your imagination runs a bit wild. So I thought I was going to be waking up with the kind of plastic bags that my parents brought home from the grocery store full of groceries and I was a little horrified at the idea that it was going to be like that. I'm very happy to say that, with the exception of that post-surgery transparent pouch, an ostomy pouch bears very little resemblance to a grocery store bag. It is actually quite a marvel of science.

**Scott**

I think people are breathing a sigh of relief at that, especially thinking about a plastic grocery bag full of human waste.

**Mike**

Exactly.

**Scott**

And your mom was actually in the medical field. Did that make any difference in this?

**Mike**

Absolutely. And she was absolutely wonderful as not just a very caring, wonderful mom, but as a liaison between myself, the nurses, and the doctors because it felt like everyone was speaking different languages. I know it was all English but when it came to me, the very young patient, I was very fortunate to have a mother who understood a lot of the lingo that was being used and was able to, in turn, explain things a lot easier to me. So yeah, I really lucked out there.

**Scott**

As a young person, every kid wants to fit in with his peers. How worried were you about how your friends would react to this?

**Mike**

Oh, that's a really good one because, even as a little kid - like, this was pre-puberty for me - there was still a fair amount of concern that I had, for sure, on that matter. I was very lucky that my core group of friends— I grew up with four other guys who all came from very different kinds of backgrounds and the one thing we all had in common was not just our location, but we were really solid, really tight guys. We all built tree forts in the local forest and spent a lot of time playing out there. So because we weren't too worried at that point yet about what the opposite genders might think of our bodies, it was kind of a good time, I guess it could be said, for me for a little bit. I was really much more happy to just be able to be outdoors and playing than really concerned about the difference in my body versus that of my four friends.

But it wasn't too long after that - a couple of years - when puberty started to kick in and it quickly did become an issue at that point. "Geez, how am I possibly going to get a girl to look at me twice when I have a bag of human waste stuck to my abdomen? This is going to be tough."

**Scott**

That's a bit of a handicap. How long did it take before you were pretty comfortable with living with it?

**Mike**

It took a while. After speaking with a lot of other ostomates who had their ostomies done much later in life, I think it really was a blessing that I was as young as I was in the sense that— because you're still forming who you are in your own mind, it just kind of became one more ingredient in the recipe of becoming yourself. It would have been neat to be a teenager and not have to worry about those things but you're dealt the hand you're dealt and there's really not much you can do about those things, so I ran with it as long as I could - still am.

I would say that it probably took a few weeks to a few months before I could move around in a way that I didn't feel, well, for lack of a better word, crippled in the first couple of weeks as your abdomen is healing from the very invasive surgery. Your whole body feels so crippled by the whole experience and also just the amount of blood loss that I'd gone through and the really rough feelings that I had leading up to the surgery. You're just kind of spent. Like, it's hard to kind of get a grasp on what regular life is going to feel like in those early days.

But I would say that as those scars were healing somewhere between the one-month and the six-month mark— and I'm sorry, it's been three decades. I know that sounds like a large window. If a new ostomy patient can just let those initial scars heal, I can tell you with certainty that your body kind of does get back on track. It's just getting over that initial shock, both the physical and mental side of having a body that works a little bit differently than the one you were born with.

**Scott**

When you first got it, did you ever go absentmindedly and sit on the toilet without thinking about it?

**Mike**

That's so funny. Maybe not completely absent-mindedly but it was, like, my gut wanted me to. I kept having what I would refer to as ghost poops where, even though my ostomy was working

fine, everything that was going in my stomach would eventually come out the pouch, there was just something about waking up in the middle of the night sometimes. I would have this little “What the heck is going on?” feeling. I feel like I have to poop the old-fashioned way and I would sit on the toilet. I don't know entirely how often this happens but I have heard of amputees who will wake up in the night and scratch an arm that's no longer there and hasn't been there for many years. That's, I guess, the closest I could relate to that because it did take a while before my body stopped doing that where the automatic reaction to a cramped gut was like, “Oh, I have to go sit on the toilet.” Nope.

**Scott**

Now, this is a question that I've been wanting to ask you ever since we first spoke. You said that you've been in martial arts. Didn't you ever worry about getting a kick right in the bag.

**Mike**

Which did happen several times?

**Scott**

That sounds like it's a big mess.

**Mike**

It could have been shitty. I'm sorry. I'm sorry. I had to say it at least once. So again, being pretty young when this happened, I think a lot of teenagers will also overcompensate whenever a trial is placed before them and I don't think I was any different in that respect. So it wasn't just martial arts. I also spent some time as an army cadet in our local army corps. I did pretty much everything I could think to do that I felt an ostomate was told they shouldn't be able to do just because I wanted to see if I could. It turns out that ostomy products are so strong that you really can do the vast majority of things that a person without an ostomy can do quite safely. I can tell you I have taken many kicks to the pouch and had no issues.

Now, I don't want to imply that issues can't happen with a pouch, especially when there are some mechanical difficulties that you aren't aware of, but that isn't the norm. I really want to stress that it's not the norm. Also, to anyone else who is an ostomate who might be considering any kind of whatever strenuous physical activity, just be open and honest. If you are about to get into a match with someone, just make sure they know you have one. Chances are, they're probably not going to repeatedly attack that area of you. If not, then you're not sparring with the right person. Yeah. But it is such a marvel of science. Today's ostomy pouches can really take a beating.

**Scott**

Can you talk about the first time you had an accident with the pouch?

**Mike**

Yeah, absolutely. As I said, although they can take an awful lot of damage without an issue, accidents can and still will happen. I went through middle school without any real problems and was actually kind of starting to think that maybe accidents couldn't happen. One day, at the end of a usual day of high school, I was rushing to catch the bus with some of my friends. In my rush, I still remember I had these— I was a tall, skinny kid. As I was running, my very long legs were pumping quite furiously when all of a sudden the clip at the end of my pouch that kind of holds back the nightmare caught on the inside of my boxers and just opened up. Because I was running as fast as I was, just pumping away, it meant that I was kicking all of that horrible

material all the way down my pants, leg, right to my socks, right into my shoes, and this was happening just at the end of a school day.

I went to a pretty busy school. We had about 1,800 students at our school. Just as everyone was filling out past me, I looked down and I could see that my right leg was no longer denim blue. Like, my left leg was— it was nightmare brown the whole way down. So that one really caught me by surprise because, again, I never had an issue before and this was so severe, so fast, so public, and it was just all of my early nightmares just kind of came crashing down to me. I could see my friends who were maybe a hundred or 200 feet away from me on the bus who had made it and they're yelling at me to get there.

I just couldn't think of what to do for a second. So, I had a quick look around and I could see the bushes on the other side of our football field. So I just ran as fast as I could to those bushes and I hid there until there were no more kids available and all the buses pulled away. I was really not sure how I was going to get home. For me to walk home at that point would have meant about a two-hour walk down a very busy stretch of road.

I knew that right out across the street from our school was a local wave pool and I felt very James Bond. I just kept my eyes peeled to make sure no people were coming in or out. I waited for my opportunity and I sprinted as fast as I could to get into their public washroom, and I chose the handicapped washroom knowing it would be a little more private, locked the door, and waited until I could hear some footsteps. Because, again, this was the very early nineties, there were no cell phones, so I couldn't call for help at this point beyond trying to get the pool attendants' attention, which I did ask them politely to call my mom at her work and ask if she would be able to bring me a fresh pair of clothes at the public wave pool. So it took a very long time and I can't even tell you how long that was. It was one of those. It could have been five minutes, could have been five hours. It just felt like an eternity to me.

Eventually, my mom did show up, she snuck me in the fresh clothes along with a plastic bag for the old ones. I got home and fixed everything up, but things felt pretty dark for a little while after that because your world changes fast with that kind of mess.

### **Scott**

At that point, I'd have a lot of trust issues with that pouch.

### **Mike**

Well put. You're right. Yeah, I really did. I spent a couple of weeks after that not really taking any chances. I went to school, I finished school, I got off the bus, went home and that was it. But, really Scott, especially at that age, so many awkward, embarrassing things are happening to not just yourself, but your friends at every hour of every day. It's just teen years. It's just an awkward time. I can tell you that a lot of my other friends had maybe not the same category of issue but they had a lot of their own self-confidence issues. Again, I'm so fortunate to have had the friends that I've had. It just became clear to me that I wasn't doing myself any favors, staying locked up in my room playing Nintendo, just scared to death that same nightmare incident was going to happen because I knew that I already had, at that point, three or four good years with an ostomy and there was nothing saying that I couldn't just take a little more care to figure out what happened that one time and just make sure that doesn't happen again.

I don't do running in jeans anymore. The heavy fabric is really what caught on to the pouch issue at that time. So yeah, if I'm running, I just make sure I have appropriate running gear on

and just make sure that the skin around the stoma. Stoma, by the way, is the name of that little, little piece of intestine that has been brought out of your abdomen - your man-made butthole. So sometimes the skin around a stoma can get a little bit rough and, in those times, it's a little harder to get sweating exercise in. You can still do a lot of sit-down exercises to keep you busy. But yeah, I still had a great many years of high-intensity activities including martial arts where I had a lot of fun growing up.

**Scott**

I would say, if you're at a party, and the question comes up "What was your most embarrassing moment?", you get to let everybody else go first because yours is going to beat all of theirs.

**Mike**

Yep. I will take that trophy if it's available.

**Scott**

And, again, still thinking about the teen years, and even forward or even past that, just being in this situation kind of makes you different from other people. Of course, we're all different in various ways. Has this ever led to you having any form of depression or thoughts along those lines?

**Mike**

Absolutely. I really appreciate the chance to talk about that. It comes in waves, and I think that's probably pretty true of anybody in any traumatic circumstance where, at first, once you get that ostomy, you have to deal with a lot of the issues of living with a new type of body, but you're so jazzed that there's an actual end to the pain and suffering of having a diseased intestine because that was really rough. That was really, really hard to get through. It's a lot of mixed feelings right out of the gate there. As you get better, you really learn to enjoy every sunny day, and any day that you can get out and about and do your thing is a really good day, and you start to feel really good about that, which is great. You kind of reenter society and just be a normal person. As time goes on, there's going to be some other hits or misses that'll hit you that do make days a little more difficult to deal with.

In my youth, I used to do a lot of counseling for new ostomates, especially at the children's hospital where I went through my ordeal and I felt really good and happy to do so because I was on top of the world again. Sure, my body worked differently than the average person's, but I wasn't letting anything stop me. So I had a really good go for a lot of decades. It wasn't until actually kind of my late thirties or early forties when life got really hard again with stuff that had nothing to do with the ostomy. My marriage broke up. My ex-wife and I were still wonderful friends, but that was a hard time. We lost our family business together.

I have a son who I love dearly. He's a wonderful young man but he went through a lot of his own health issues too and they weren't necessarily tied to the same genetic disorder that I had, but it was just a really rough time. He's healthy now. He's great. He's doing wonderful. But it was just a lot of rough things that happened in a very short period and that can happen to anyone - it really can. I felt at that time, even though I lived all this time with an ostomy, I found having the ostomy really made it hard to get back on top of things.

Along with having had ulcerative colitis, now later in life, I'm getting a few more autoimmune disorders. So I now have psoriatic arthritis that comes and goes in a lot of pretty hefty flare-ups. When these hit, it feels like they can hit really hard and I'd be lying if I said that I didn't have



some really down periods. So I think it's really important to kind of think about the long-run situation of mental health when it comes to these things because it is something that, if left unchecked, you really can do a lot of damage to your own psyche without even really realizing that you're doing it. So to anyone who is a new ostomate or even an old ostomate, I highly recommend to be open with your doctor.

I think it's really important that anytime your doctor starts to open up any conversation with you about the mental health side of things, not just, "Hey, Mr. or Mrs. X, I see your ostomy is working fine, but how are you? How are you feeling?" I think it's really important to talk to your doctor immediately upon feeling more than just a little down. It's true that we all get a little bit down, but it's really easy to kind of lock yourself away and think that you're the only person experiencing these problems. Really, Scott, the truth is, since I've been talking about these issues a lot more in my middle-aged years, I've spoken with a good deal of people who are just getting into having an ostomy now and they sound devastated - they do. There's also a lot of hope. I mean, there's really no greater second chance than being told, "That's it. You're on death's door. Wait a second. Here's a whole new life. It just means that you've got a bag of poop stuck to you."

**Scott**

Option A or B. I'd say, yeah, you take the solution.

**Mike**

Exactly. So it's just really important to make sure that, while you're dealing with these things, you're open to talking about the harder side of stuff too because you might feel alone when you're in your hospital bed or your situation at home, but you're really not. There's an awful lot of people out there who are dealing with this kind of stuff, so you're not alone.

**Scott**

You mentioned that a lot of the new people that you talk to are seeing hope. That's because of you. You are providing hope just because of having gone through this. Again, I think what they want to hear is what it is really going to be like. But let's talk about some of the day-to-day stuff, just the usage. Can you get it wet, take a shower, or go swimming?

**Mike**

Yeah, absolutely. That was a good one too because I was really concerned about that as a kid. We had a local pool in our community and that pool meant a lot to me, so I really wanted to get back into it. It turns out, yeah, you really can. You can absolutely get your pouch wet. Pouches have come out quite a long way in the last 30 years. But one thing to keep in mind is you also want it to have a chance to dry out. When you're having your shower, don't be afraid. You can get it as wet as you like, scrub everything, get everything all nice and soapy. After your shower, you really want to take extra care to make sure any of the fabric has a chance to dry out completely.

It sounds kind of funny. Once upon a time, I used to use my ex-wife's hair dryer on the cold setting just on my pouch. It just looks funny the first time but it just becomes part of life. It is okay to get wet. Absolutely.

**Scott**

How often do you have to empty it? And how does that work? How do you do that?

**Mike**

There are two kinds of things to keep in mind. Often, when I'm asked how it's emptied, people aren't actually aware that it's a drainable pouch. The pouch that I use— I have a little clip at the end that I open up and I empty into the toilet anywhere from five to ten times a day. I know that sounds like a lot, I recognize that, but I'd also like to stress that if you consider how long it takes to empty an ostomy pouch, it takes about as much time for me to do my business as it takes most people to go for a pee. So yes, I go to the bathroom often but it doesn't mean you're spending your day in there.

**Scott**

When the waste passes through from your stomach into the pouch, do you know it's happening? Is it involuntary?

**Mike**

It depends on what kind of foods I've been eating, and it is involuntary. There is absolutely no way that I can really control what's exiting my body and entering the pouch. In fact - and this is something I really want to tell any listeners who might be new to having an ostomy - it's kind of a pain but the harder you try to flex your stomach and hold it in because maybe it's not a good time to be making these little gurgly swamp sounds - maybe you're on a crowded bus - but the fact is the more that you clench your stomach trying to stop it from happening, the funnier those noises are going to sound, the more it's going to sound like you're strangling a bird in a swamp. I can tell you your best bet is to relax and take a deep breath. It's going to happen. There's noise. You can't help the little gurgling sounds.

**Scott**

You mentioned on, like, on a crowded bus. Of course, there's going to be background noise anyway. People might not even hear it. But even if they do, everybody's stomach gurgles and growls sometimes. Wouldn't they just think that's what it is?

**Mike**

As long as you are calm and cool about it, that's exactly what it sounds like. It's as soon as you start flexing while your body's trying to get rid of it— if you can picture that noise of— if you've got a balloon that you're pulling on the ends of the balloon as it's deflating, that's the noise it makes if you try to stop it. That's why it's just really important to let background noise and other people's natural digestion sounds kind of be the mask for what's going on down there, if it's really a concern for you. But by and large, it's really not much of an issue.

**Scott**

Do you still fart?

**Mike**

Great question.

**Scott**

I got to tell you, that's the first time I've ever asked a guest that on this podcast.

**Mike**

I'm honored to be the respondee. Yeah, I certainly don't fart out of the old area. In fact, there's nothing there anymore. This is also a common question. What happened to the old exit hole? Well, it's simply sewn up. There's nothing but a puckered scar to remind me of a previous life

that's down there now. So there's no action at all from the butt. As far as the pouch goes, it does pass gas. I don't eat a lot of food during the day just because it doesn't take long after eating before the pouch fills up and you do spend a lot of your day in the bathroom then.

My own daily routine involves a lot of coffee during the day, a little bit of light snacking, and then a good solid couple of meals later into the evening. So during the day, you're not going to hear too much at the end of the night after I've had all the calories that I need. It's not even necessarily that you're going to hear very much because, like I said earlier, I keep my stomach pretty well relaxed, especially after food. But yeah, you might hear a little noise.

The few times that I've been around other people who, for whatever reason, have no idea that I have an ostomy, that noise will happen and, of course, it's hard not to kind of turn ahead when that happens, but I'm always happy to explain to whoever has heard it. "Don't worry. It's sealed. You're not going to smell a thing," which of course leads to a longer conversation. Yeah.

**Scott**

What an icebreaker. Does this change how you would normally sleep?

**Mike**

Yeah, it does. I still remember as a little kid, I was a sleep-on-my-stomach kind of kid and that changed overnight. I have not slept on my stomach since 1991. It's been a long time. I will sleep on my back and sometimes on my side too. It is just really important to make sure that, if you've got anyone in bed with you, you're just sleeping on the side of the bed that is conducive to sleeping on whatever side your pouch is on. For me, my pouch is on my right-hand side, so I'll sleep in sort of the fetal position on my right-hand side. That's okay. When I have company or a guest or if I have someone sleeping on my left side, it just means that I can't turn to see them.

**Scott**

Okay. That's all. Have you ever randomly met someone else in public with an ostomy and it's, like, your best friends automatically?

**Mike**

Yes, that has happened. Once upon a time, I was working in a big box home renovation store. I was working in the lumber department and I had been there for quite a while. I was friendly with everyone but there was one dude who was a friendly-enough guy and we would have breaks together and we'd chat a little bit about movies and games and stuff, but it was still kind of a work friend. We didn't really get into things too much. Then, one day, he got very ill. I won't get too much into the background of his illness but I will say that he was super despondent on one particular day and informed me that he found out he was going to have an ostomy done, and he had no idea that he was talking to someone who had an ostomy for years and years.

**Scott**

That is amazing.

**Mike**

It was pretty cool. I still feel really bad for the guy because, again, he was a lot further along in life than I was whenever this change came to him, but it did my heart good to be able to put my hand on his shoulder and say, "Listen man, I promise you that this is not the end of your life. In fact, you are right now talking to someone who has spent three decades with a pouch. I've worked with you for months now and you had no idea that was the case at all." It was really

good to be able to do that with them and, not really a surprise, we got a lot closer after that. We talked about awesome new supplies all the time and shared different experiences.

**Scott**

You guys had conversations in the lunchroom that others couldn't really join in on. I imagine very much a lot of people find pooping kind of relaxing. Do you miss that?

**Mike**

Oh, great question. Yes. And you know what? More than anything. Whenever I'm at someone else's house and I still see a magazine rack or just an old Archie book that's sitting up there and I'm like, "Oh yeah, people use this time for relaxation. Man, that's so cool." So yeah, unfortunately, I don't really have a lot of sit-and-ponder moments anymore. I'm going to share something with you. I have not sat on a toilet to poop in over 30 years but I have, at certain jobs, run to the bathroom to sit down for five minutes of peace because I do miss that. I missed having a time and place where you could close the door and the world just respects that and leaves you alone.

I've had a couple of different manager positions over the years, and I really love managing. I've spent a lot of years managing an art store and that was really my favorite time of life, but it was also very stressful. I felt like I had people knocking on my office door every six seconds and even going out for a break— people would find you out on your break, but there's just something magical about that stall door. As soon as you sit behind that stall and you close that latch, people leave you alone. That's an unwritten rule. So that's what I miss. That's what I miss more than anything. But because my last few memories of pooping were so awful - Scott, they were so bad - that whenever I'm like, "Geez, I wish I could sit down and read an Archie book," then when I remember what those last few pooping times were, it really makes the time I have in the bathroom now not seem so bad.

**Scott**

Since you no longer have a butthole, how would you have a prostate exam?

**Mike**

Also a great question. That was one that I made probably into my late 20s before it occurred to me that, "Hey, I should probably talk to my doctor about how the heck that's going to work." So a prostate exam, for me, it's primarily done with very expensive tools, an MRI machine or a CAT scan. The usual method that a doctor has of performing a prostate exam is a bit shocking, I think, to most men whenever they see the doctor putting that glove on, but the main reason doctors go that route, as uncomfortable as it is for men, usually is because of how easy it is to do. It is a very easy exam for a doctor to perform that way whereas the cost and time of setting up a CAT scan is pretty excessive. So a lot of other people, I'm sure, would much rather have a CAT scan to have their prostate examined as opposed to the doctor's finger. But I kind of chalk that up to being one of the sprinkles on the cake of having an ostomy. I just don't have to go through that terrible glove test.

**Scott**

And of course, we should mention you're in Canada. So the Canadian health system is certainly very different from the US healthcare system. But in speaking of expenses, what costs do you still have today as sort of an ongoing thing?

**Mike**

That is a great question and point and I really thank you for bringing that up. I recognize just how lucky I am to be born into a developed part of the world that has a great healthcare system. I can tell you that one of the first questions that I asked my ostomy nurse when I was 10 or 11 was, "What do kids in third world countries do when they have an ostomy?" Because at that time, I was just so amazed at how good ostomy pouches were. I had just learned about them properly and was so just marveling about them. But yeah, I had to wonder, like, what happened to some poor kid in a country not as lucky as mine. She told me the sad fact that there are kids on this planet who are running around with empty coffee cans and duct tape and that just broke my heart. That was crazy. As rough as everything I'd been through was, at least I'm in a country where I do have a good amount of help.

I live in the province of Ontario. Twice a year, I get a check that does help balance a little bit of the cost of ostomy supplies for me. It doesn't cover it entirely. I do still have to pay out of pocket and it's also a set amount. What that means is in the years or in the six-month periods where I am going through a lot of ostomy supplies, which does happen, then it does get a little costly. As grateful as I am for the help that I do have and for the quality of the ostomy supplies that I'm using, I can still be out a couple hundred bucks every month - worst-case scenario from this.

I'm right now getting through a rough flare-up of both psoriatic arthritis and psoriasis. So the skin all around my stoma is really rough at this particular point in time. So I'm going through one pouch— even though I empty a pouch 5 to 10 times a day, I keep the same pouch on ideally for five to seven days. That's wishful thinking. Lately, it's been every one to three days. So because of that difference, it does mean, at the end of the month, it's costing me about \$200 to \$300 a month.

### **Scott**

Since you first got your pouch, has that or the process improved much as far as the technology or the materials used?

### **Mike**

Oh, yes, absolutely. And again, I really appreciate you asking this question because it was one that I failed to ask myself for decades and it cost me a lot of comfort time. Now, when a person first gets an ostomy, there's going to be an adjustment period of trying to find the pouch that works right for you. There's quite a lot on the market, so you're probably going to go through a few different pouches. In that time, you're probably going to have a few bad experiences that will really put you off looking at other options once you find one that works for you at all.

I was in my early thirties before I finally marched into the ostomy store and I said, "I want one sample of everything. I want to see what's on the market." When I did that, my world changed for me. Previous to that, I had been wearing pouches that were just pure plastic from top to bottom and I would get— in the summertime here in Ontario, we get some pretty muggy summers and I was getting all these heat rashes between my leg and the pouch. Well, for quite some time now, what's been available is this microfiber that covers the entire pouch. That fiber does a wonderful job of acting as a barrier between plastic and my skin. So it just means every summer, I can go the whole summer without that age-old rash that I used to just think was part of ostomy life when it didn't have to be for any reason. That's just one of a few different improvements that they've made over the years.

Also, the seal that goes around the pouch. For me, I use what's called a two-part pouch system where there is an adhesive flange that gets cut to size and put around the stoma. And then,

there's the actual plastic pouch that, with a kind of Tupperware-type seal, attaches to the flange. Where that Tupperware seal is has also come a very long way because, when I was much younger, a certain amount of weight in the pouch— as the pouch fills up, it gets a little heavier. Sorry, this might be a little more info than some of your listeners are looking for but I'm just going to share this because it's practical. What you eat also greatly affects that - eating a lot of high-carb stuff, really dense foods, lots of pasta, lots of oatmeal, stuff that's easy to eat and easy to pass. However, there's a lot of weight to that stuff. My first couple of pouches— I did have some issues with the weight of the pouch, anytime I would stand up, as it pulled down, it would put a lot of stress on that Tupperware seal. Today's Tupperware seal that they have around there is a million times better. I haven't tested it but I feel like I could hang a cinder block from it. And as long as my skin is in good shape, the pouch holds.

**Scott**

I don't know. Maybe I should contact Tupperware to sponsor this episode. I mean, I'm not sure they would be interested in that.

**Mike**

Well, I don't know who owns the patent on the pouch that I use, but it's there. They do a marvelous job.

**Scott**

But yeah, when painting that mental picture though, everybody knows what the Tupperware seal is like. It's a good thing to use. Is there anything about this whole experience that you've actually liked?

**Mike**

Oh, well, it's nice to feel different and unique.

**Scott**

I love that outlook.

**Mike**

That I've actually liked— well, there are times when things are working well with your ostomy where it actually can seem like a little bit of a blessing at times because when I think of all of the pain and roughness of diseased poop time, it was the worst, obviously. Even just some of my friends and family members who just have to go through some of the regular trials and tribulations of pooping out of your natural buttock, it sounds rough and crazy, maybe, but again, if you can keep in mind that I've been pooping this particular way for 30 years now, it is bizarre to me that when I'm shaking someone's hand, I'm probably shaking the hand of someone who wipes their butt with their hand and little tiny bits of toilet paper. It's actually quite bizarre to someone when they've gone 30-plus years of a no-fuss, no-muss exit system.

**Scott**

If someone's listening to this and they happen to know a person, a friend or a relative who has just gotten an ostomy, how should they handle talking about it? Do you just avoid the subject completely or what's the best way to approach that?

**Mike**

No, I wouldn't avoid this subject at all. Now, it does depend on the person. I'm a very open guy. I like talking about it and I like sharing the many hurdles that have been jumped over to live a

really full and productive life. But I've met a lot of other ostomates who weren't in that headspace at that time, so it's not necessarily something that shouldn't be talked about at all. It's really important to ask how they're feeling about a particular subject. I have to say it this way. I can talk shit all day, Scott. To me, it's nothing.

**Scott**

It's your normal.

**Mike**

Yeah, exactly. But I think to someone who is just getting their heads around the fact that this is their new life, this is the new them, it's good for them to actually hear it talked about in a normal way. And if you are the friend or loved one of someone who was going through this, the best thing you can do for them is, if you have a little joke to make on the subject and it's something that person normally - when they're in good spirits - would joke about, make the joke and go with it. Just let them know that it's not the end of life at all. In fact, again, after 30 years of this, I feel like I'm living proof that it's definitely not the end for you. So the faster that you can talk about something, get it out in the open, and if there's any mercy in the world to have a laugh about it, then the faster that person is going to be feeling more like their regular selves and able to get on with life with an ostomy, which is some pretty amazing shit.

**Scott**

Okay. I want to ask you this. What's your message to anyone who might be about to go down this path? They've been told they're going to have an ostomy. What would you say to them?

**Mike**

It's not the end. You're going to be okay. It doesn't feel like it right now. I'm sure the upcoming change is terrifying. It's scary. It's maybe the scariest thing you've ever dealt with, but the idea that you have found yourself in a position that you and your doctors are talking about, that means that you have been through some really terrible rough times. There's no way that your doctor is, "Hey, are you bored? Go get an ostomy." Nope, that doesn't happen. Ostomies happen for people who are at death's door one way or another. It's going to be different. There's going to be some adjusting, but I promise you it's going to be better than whatever you've had to deal with to get to where you are today.

**Scott**

There are resources out there available for people. A few that I know of— there's a subreddit called ostomy. There's a website community called ostomates. Is it ostomates or osto-mates for that community?

**Mike**

So there is ostomates. I believe there is an osto-mates - that's a dating site for people with ostomies, which I highly encourage giving a try. And then there is ostomates, which is just, people just living with an ostomy and that's it. And there's

**Scott**

And there are lots of Facebook groups as well which you can join.

**Mike**

Absolutely.

**Scott**

And a future resource— you're writing a book about your experience. We'll look forward to that.

**Mike**

I very much hope to have that out by next year.

**Scott**

Awesome. And for anyone who wants to contact you - you have graciously said that it's okay - we will have your email address in the episode notes. People can find that and contact you if they need to. I contacted you about doing this podcast conversation and you were a hundred percent up for it. You can tell just by talking with you, you love getting this information out there, and I appreciate that, and I'm sure a lot of people do as well.

**Mike**

Ah, Scott, I can't thank you enough for reaching out to me because you're right on. I very much do appreciate the chance to talk about this subject. I think it's something that a lot of people have a hard time talking about and it shouldn't be that way. So thank you very much for this opportunity.

**Scott**

Here's a fun fact – Mike and I have been trying to record this conversation for the podcast for almost a year. He had some health issues, then we had technical problems, then scheduling conflicts. But he and I are both people who don't give up very easily, so I'm glad we were finally able to make it happen.

And as I mentioned, we have lots of resources in the episode notes, and you can also see a picture of Mike there – that's at [WhatWasThatLike.com/175](http://WhatWasThatLike.com/175).

Okay, are you looking for a new podcast to listen to? Here's one that I subscribe to – and it's a voice you may have heard before.

A few months ago I released an episode called Laura's Pain Became Her Purpose. Laura told the story of losing her little boy, Anderson, to a hot car death. If you haven't yet heard it, I highly recommend that you listen to that episode, because the summary I just described is not even the whole story.

And now, Laura Beck has launched her own podcast. It's called Beck's Backseat to Change, and she is on a mission to get her story and her message out to parents with young children, and anyone who knows those parents. She just has a few episodes out now and she's doing an amazing job. Part of what she's including are stories of "near misses" – this is when someone might forget and leave their child in the car, but they remember quickly enough so that the child is unharmed. And it can happen to anyone.

You can find it on any podcast app – just do a search for Beck's Backseat to Change. Personally, I recommend starting out with episode #2, titled "Empty Boxes and Near Miss #1" – but you'll want to go and listen from the beginning anyway. Her new episodes go right to the front of my playlist.

Graphics for this episode were created by Bob Bretz. Full episode transcription was created by James Lai.



And now, we're at this week's Listener Story. We do this for every episode, and it's just what you think it is – a story sent in by a listener. These are just 5-10 minute stories, and really they can be about anything interesting that happened to you. If you're not sure if you have one, here's a prompt – what was the time when you were more scared than you have ever been? I know you have a story like that. Record it on your phone and email it to me – [Scott@WhatWasThatLike.com](mailto:Scott@WhatWasThatLike.com).

This week's story actually fits in with the theme of today's episode – it's about a gastrointestinal emergency.

Stay safe, and I'll see you soon.

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(Listener Story)

This is a bit embarrassing, but Scott is one of my favorites so I don't mind sharing it with him and with you. I'm going to take you back to the year 2000. I was getting ready to graduate from college. I went to Ohio University. That's where I met my future wife, Elizabeth. We were both seniors in the Viscom program. It was the school of visual communications and we were going to school to become photojournalists in our career. The seniors were a few months from graduating and everyone was scrambling to get a job. This was the time we were going to figure out where we were going to go with our careers after we graduated.

We were looking for either newspaper or magazine jobs and, luckily, I was fortunate that I had a leg up over most people. I just won a major award, which gave me an advantage to get a job and be valuable in that field. But almost every one of those jobs had to come from the recommendation of the director of our school. His name was Larry Niswonder and he can really make or break somebody's career starting out. He literally had that much influence within the industry. So Elizabeth and I got to know the staff very well. Elizabeth worked in the office there. We worked on a lot of projects together, so we got to know them.

One day, they were getting ready to go out to lunch together as a staff. So Larry, his wife, Marcy, and some of the other top professors in our school along with two other seniors went out to lunch together. This was an honor to do because we would get to talk to them more, get to know them a little bit more, get to see what was going on in this world, and what jobs were available. This was a really important lunch to go to. So I really wanted to make a good impression to hopefully get a leg up for one of these jobs coming up.

So the place that they chose to go to was Pizza Hut. Now, in college, that's a normal place for college students to go to and, apparently, some of the professors and teachers go there as well. So they invited us along, we all hopped into this big van owned by the school, and we drove to Pizza Hut for lunch. So we got there for lunch, and Pizza Hut had a buffet. Now, I'm not sure if they still do, but it was an all-you-can-eat pizza buffet, so I took advantage of that and I ate just about all that I could possibly eat. So after lunch is over, we all head back into this big van and we head back to school which is about 10 minutes away without traffic.

While everyone started talking, I immediately felt discomfort. As soon as the van started moving, I felt my stomach turn upside down. It seemed like, just in a moment, everything I had eaten had just turned on me while I was sitting there. And within not long, a few seconds, I felt like I was

going to get sick and it wasn't sick in a normal way from up top. It was sick where it would be from the bottom. I needed a bathroom and I needed a bathroom quick.

The problem is I didn't feel comfortable saying anything or asking them to stop. Everybody's talking. We're stuck in a little bit of traffic and I am now clenching while the van bounced around hitting every pothole while I was living in hell. Elizabeth was sitting right next to me. She had no idea what was going on. With clenched teeth, I told her what was happening and she felt awful. She didn't know what to do. She grabbed my hand and tried to help me.

The van's barely moving, we're stuck in traffic, and I'm crossing my legs, hoping upon hope that the worst doesn't happen. So now my head's against the window, sweat is coming out. At the same time, I'm mentally processing what's going on. Physically, I'm in the worst pain that I've been in forever. That was the first part. The second part is I'm about to have maybe the most embarrassing moment of my adult life. And the third part of that all is, with the pain and with the embarrassment that's about to happen, this embarrassment would happen in front of the most influential people in my career who can make or break me getting a job, all the hard work that I've done for all this time is about to go down the drain and down my leg.

Every time we have to stop at a stop sign or a traffic light, I would have to brace myself to make sure and to try my hardest that didn't happen. At one point, I pretty much gave up. I had my head down, I groaned, and I pretty much envisioned the hell my life would be at that university for the next two months with everybody knowing what just happened. Elizabeth held my hand. She told me to hold on, "It's getting closer." It was a race against time now to get to this building. I looked ahead. I knew every street. I knew every turn on how to get there but they weren't in nearly as much of a rush as I needed them to be, and we were so close. There was one more traffic light and that was my final frontier. I needed to get through that. I wasn't out of it yet. We had pulled into the parking lot. We were so close, but it was still so far away. Even at that point, I thought I didn't even care if an accident happened but just make sure I'm out of the van when it did.

I'll never forget seeing the building, pulling into the parking lot, me getting out and running toward the building. I can't even imagine what I looked like running towards that building, struggling to get that door open, getting into the bathroom, and preserving my career. Nobody but Elizabeth had any idea that any of this was going on.

It wasn't more than two weeks later when Larry Niswonder called me into his office and he told me that there were two job openings in Evansville, Indiana. They wanted me and Elizabeth. That was such an odd thing to happen. It was so difficult to get two jobs together and he was offering that to us. We accepted the job a month and a half later. We had started our staff positions at the Evansville Courier and Press. Two years later, Elizabeth and I got married. Three years after that, Elizabeth gave birth to our first son.

Now, all these years later, we've been married 21 years, and we have three sons. If things would have gone differently at Pizza Hut, there's a good chance that none of this would have happened. These children might not have been born and I might be looking at a completely different life and career if they would have driven just a little bit slower.