



Question and Answer

Morgan Stout:

There was another really great question along that same line about having other people help you with that. What would a good thing to tell people briefly, either on a medical alert bracelet, or just if you're in an emergent situation that would quickly and easily convey that you have an Indiana Pouch?

Cindy B.:

I have medic alerts, so it's all on that for me. And like I said, both of my daughters and son-in-laws, and my husband all know about it. So they would fill anybody in any way.

Dr. Aaron Laviana:

What about you, Scott?

Scott R.:

I really hadn't given it any thought. I mean, it's become such a natural process for me and in my mind, I'm still younger than you. So I don't think about it, but now that I am... Now that I've heard this, maybe I should wear an alert. I am diabetic, well controlled and you know, it wouldn't hurt to have something immediate information should something happen that makes me unable to communicate. So yeah, I don't know the best way to go about providing that a bracelet or something else. I don't... I have to look into it, I guess.

Morgan Stout:

Dr. Laviana, is there something that you would see on a medical alert bracelet that would tell you exactly what you needed to know about somebody who had an Indiana Pouch?

Dr. Aaron Laviana:

So I've seen patients who literally have it say Indiana Pouch on there. I mean, God forbid you get found down or there's a skiing accident or something, Scott. It's that way somebody knows if you go to just the first emergency room there, they're going to look and really be confused as to how to proceed. And so it's just as simple as saying, Indiana Pouch can really go a long way.

Morgan Stout:

Thank you.

Scott R.:

Interesting regarding Indiana Pouch. So I'm playing some physicians really aren't even familiar with it. I kind of had to explain the procedure to one of my primary care doctors. And just what I've heard of it, but it's that like a neobladder? And I guess there are differences that they need to be aware of.

Morgan Stout:

It would seem that simple phrase of just Indiana Pouch gives the provider enough information to either do a very quick Google search or they'll know what it is. So I hope that answers your question. Speaking of primary care providers, we had a really good question about should primary care providers or a urologist do your annual/semi-annual urine check or what the importance is in communicating that with your healthcare provider about what needs checked in the urine?

Cindy B.:

Before I had Dr. Laviana, Dr. Kraus would send the orders to me and I would take them to my primary care and he would run the test and then I would get the results and I'd send them back to Dr. Kraus down in San Antonio. Now I let Dr. Laviana do it.

Morgan Stout:

Dr. Laviana, do you think it's important for the urologist to do it as opposed to the primary care person?

Dr. Aaron Laviana:

I don't think that's black and white. There's no black and white answer here. I think it really depends on the patient's relationship, both with the urologist and primary care provider, if they have a great primary care who they trust and communicate the labs back and forth, I think that's fine. One thing to worry about over time, same with the neobladder as an Indiana Pouch is that because you take so much intestine, you can get acidotic or increase acid load and you can have sort of kidney function deterioration with time. And so someone has to be vigilantly following your labs at least annually, to make sure your kidney function is good. And then as Cindy said earlier too, you can definitely get vitamin B12 deficiency, which isn't always checked. And so you have to be aware of that. And then I typically start a year out, you can probably wait a little longer, but again, because you're harvesting small intestine, as well as colon, it's interacting with urine, you have to start checking urine cytologies, which is a urine test, just to rule out a secondary cancer that can form in people who have had these pouches for 10, 20 years here. So it's something to keep in mind.

Morgan Stout:

Right. Scott, what is your experience with having your urine checked?

Scott R.:

Well, you're always going to show an elevated white count because you're catheterizing to give the sample. So a primary care who say, you didn't know you had an Indiana Pouch would say, oh, we better start on Cipro, do a urine culture, which I get once or twice a year, but I think it can be over-prescribed antibiotics when just drinking a lot of fluids irrigating and washing it out. I mean, when you get up to a

white count in the way up there, yeah, you probably need some type of antibiotics, but right now I had an urinalysis done for a minor surgery I'm having, and it was like a hundred, which was potentially, I guess, I don't know, five to 10 times abnormal. And I think a normal general practitioner would've started you on antibiotics where I didn't have any symptoms and my infectious disease doctor, as well as my urologist says, if you're not having symptoms, let's not start you on antibiotics. So I think it's something that needs to be... People need to be aware of you just because you have elevated white counts and so on doesn't necessarily mean you need to jump on antibiotics.

Morgan Stout:

Absolutely. And we had a couple of very related questions submitted and they're about long-term ownership. One is about an overly stretched pouch, and one is about continual leakage. So we'll start with one and then we'll move to the other. And the first is, can a pouch become stretched out and floppy over time and more difficult to empty as time progresses?

Dr. Aaron Laviana:

Yes. The short answer is that yes, it can definitely get too enlarged and I've seen these as large, definitely as large as a liter, if not 1500cc. And in that case, it's not a perfect sphere to start as a circle, but then the lobulations and the shapes kind of get all over the place there and it can get much more difficult to empty. And that's when you really get at risk of urinary tract infections, as well as stones. The problem with getting a stone in these Indian Pouches is it's not as straightforward in operation all the time as opposed to getting kidney stones the old fashion way. So it's something to keep an eye out. Scott, you're saying you're catheterizing every three hours and can you expand? And I would say ideally, yes. The answer to that is you can expand where that sweet spot is really four to 600cc of urine, but oftentimes you, especially with having it for so long, you can't expand rapidly and this will be something you have to expand 5%, 10% of the time and see how you do and go from there.

Scott R.:

Three to six hours doctor. So during the day I'm drinking so much fluids, alkaline water system in my house, exercising, walking. So three hours, but at night I'll get up to six hours of uninterrupted sleep. So...

Dr. Aaron Laviana:

Yeah.

Scott R.:

But you're saying after five years, the potential for the pouch to still be able to expand more is a possibility?

Dr. Aaron Laviana:

Yes.

Morgan Stout:

That's good to know both that it can continue to expand, but B that it also may get a little bit floppy and difficult to release that urine. Is there any sort of fix for that floppiness?

Dr. Aaron Laviana:

Unfortunately not really without an absolutely major operation that oftentimes is not worth undergoing. There's no easy fix to that.

Morgan Stout:

I'm sorry to hear that, but we'll cross our fingers for future fixes. The other question related to longtime owners is about leakage. And what about when people experience leakage past that normal thing beyond the normal leakiness? Is there tips tricks, Scott, Cindy, Dr. Laviana, what do you think?

Dr. Aaron Laviana:

One of the more common problems actually with Indiana Pouches is the leakage issue that can persist. You have that valve, but then you have to throw some sutures around there to try to really narrow it down. But unfortunately, it's not a always perfect mechanism and some people do unfortunately leak and leak. Now, if it's the point that you're putting a stoma bag over it or something to that extreme and is not better, then you can go in and revise these to improve upon that continent's mechanism. But one of the tricks here is to catheterize more frequently. I do see one of the comments here about catheterizing up to seven times daily. And if you're still leaking at that, and that's going to be every three hours or so, I mean, you can try even every two hours, especially if you're going to go out and do an activity and you don't want to leak during the activity is catheterizing right before and afterward. But if it's really, really uncomfortable or affecting your quality of life, I would seek a possible revision there.

Scott R.:

I had two revisions myself. One was under general and because of leakage, they repositioned my stoma, which is probably about four inches below my navel, so it's way down low. And that pretty much took care of a lot of my leakage. And then the second one was done just under local, where I developed scar tissue at the opening of the stoma. And my doctor was able to clean that up and now I'm catheterizing like a hot knife through butter. So it's been fine, but it's not unusual, I guess, as Dr. Laviana said not to that revisions are possible and they do help me out greatly. And that was in the first year and a half or two since then, I've had no need for anything like that.

Cindy B.:

I wear a little pad that I make up over the stoma just to keep it because of the mucus and it does leak somewhat, but it doesn't bother me. You know, I take it with me. I take a new one. If I need to, I take my tape, because I'm allergic to so many kinds of tape. I have to be careful what I use, but I haven't had any problem with the amount of leakage or anything that I can think of it all. And I had that one revision when it was on the right side, then we had the big one moving it to the left.

Scott R.:

I will mention an amazing product that I researched and researched. And I've been doing it for almost five years. It's called a stoma cover but this particular stoma cover I've found a company in actually Austin Medical Products that makes it, I'm not... I don't own their stock or anything, but they're just a cover and that'll hold between 25 and 28cc of leakage. And it'll start to balloon up when, you know it's filling up, even before the pain. But again, it's very useful in an active lifestyle. It's called the SG3, they make a number of different ones. It's just a flat little pad, but with great sticking capability, doesn't irritate the skin and Medicare pays for it by the way. So it's a super product and I haven't found anything

from any other manufacturer that comes close to it, even other manufacturers have recommended it when I was looking for something else.

Morgan Stout:

Thank you all so much for that helpful information about leakage. Now we're going to talk a little bit about mucus. We had several questions come in about mucus and the first, and I believe in your presentation, Dr. Laviana, you talked about how they take part of the bowel, and just because you take part of the bowel, doesn't mean that your bowel stops functioning as a bowel, even though it's now doing a new job of holding urine. So can you talk a little bit about how that peristalsis or the squeezing and expanding motion of the new pouch and stoma can sometimes expel mucus or urine and how that can be dealt with?

Dr. Aaron Laviana:

Yeah, there are actually several of these questions line up pretty well here. So peristalsis is just the squeezing of the intestines to push things forward. It's how your bowel movements basically go from your stomach all the way down to the toilet, but you still have that motion of pushing forward. And for some people that actually can make catheterizing more difficult. When you're catheterizing and the intestines are squeezing out, it can cause some pressure for that catheter. And it's also some of the concern of actually putting this on the left side and not the right side, even though Cindy you've done great with that. That's always a theoretical concern is that it's going the opposite direction there, but also with that, because it is squeezing, you can't have small amounts of mucus and urine sort of push out there.

Dr. Aaron Laviana:

But a lot of that has to do with the overall continence mechanism of that valve and how it sutured down below, if it's really in... So a couple things, if you have too much mucus, one of them is to really drink more fluid, to try to dilute some of that, to help that out, and when you're irrigating, if you're just doing irrigating with 60 milliliters of saline, you can increase that to 120 or even 180 to try to get that out. When you're irrigating, there's a comment made here about guaifenesin to thin mucus, and that actually works the same way it does for your sinuses. And I have several patients who do use that to thin that mucus out as well and it does work. These patients have done it for years and it works fine. It can make you tired and you just have to watch out for formulations that you can function well on, but that does help from a urinary or from a mucus standpoint as well. And so if it works for you, I say, great, I don't discourage anyone from that. And there's also a comment here on that line about being a dairy user and take more when the usage is up, there's not a real link between dairy and mucus production, per se. I think it's more with a hydration standpoint, but as Cindy and Scott said that their mucus production did both decrease over time. And I find that to be more of the norm, is that over time, you still make some mucus, but it tends to go away. If not, then usually it's having to just irrigate more when you are doing that catheterization.

Morgan Stout:

Great. Thank you. And another diet-related question about eating fiber to increase mucus or the correlation between fiber and mucus, is that something that Indiana Pouch users and owners need to worry about?

Dr. Aaron Laviana:

The short answer there is no. I mean, fiber just overall has so many great benefits, just from regulatory gut function in general, it'll make things move more. And then from an overall constipation standpoint and straining standpoint, you want your stools moving pretty freely. So I think that's a bigger, long-term issue than the sort of byproduct of making more mucus and it's not substantial in that regard either. So I would never tell someone to stop their fiber intake for that reason.

Morgan Stout:

Great. Thank you. We have one more question and then we have time to do a little bit of a final thought. So the final question is there a way to stretch a tight stoma or tips and tricks to navigate a tight stoma?

Dr. Aaron Laviana:

It's a common issue here and Scott said he had something along those lines. And part of the problem is you're taking this piece of intestine and bringing it up to the skin. And that's the farthest area from the blood supply to that piece of intestine. And so oftentimes that area will stricture down because it doesn't have a good blood supply and that can narrow and make it tight. You know, no one should ever be really struggling to have to catheterize. You also want to rule out a Parastomal hernia or something else that's causing this difficulty, or just a really tight angle. Sometimes the way these are positioned, you end up having almost an L or S shape you have to navigate through. If it's at the skin, it's actually... There are many options to revise those and they can be done pretty easily. Sometimes it is just dilation that can even be done in the office or a minor outpatient procedure to basically revise or redo that opening. But it just really depends where the source of the problem is, is it at the skin, is it from a hernia, is it deeper down on the angulation or is it somewhere else? But all of those are fixable.

Morgan Stout:

Great. Thank you. And my final question and kind of a wrap-up is Scott, Cindy and Dr. Laviana, what is your one tip for people that are considering getting an Indiana Pouch or what's the one thing you want people to know? Scott, do you want to start?

Scott R.:

I think a positive outlook on the surgery. Being positive well before your surgery and getting in physical shape, physically, nutritionally and emotionally. People say there's support groups and things like that, it's not that much different than anything else that I've had to do. I'm voiding a little differently, but other than that, it hasn't affected my lifestyle that much. And in all, thank God I got it taken care of and I wouldn't change anything or I would, I wouldn't have to have cancer, but other than that, it's all good for me. And I'm positive about my experience.

Morgan Stout:

Great. Cindy, what would you tell... What's the one thing you would tell somebody?

Cindy B.:

I agree with that, but I would also say go into it with knowledge, do your own little homework to figure out if this is for you, but don't be afraid of it because it really changes your life for the better. I would say that it does not change your life for the worse. It changes it for the better, and you got to have a happy attitude. You got to keep a positive attitude and keep God on your side. You got it made. Good doctor. It's good.

Morgan Stout:

Great, Dr. Laviana, What's the one thing you would say?

Dr. Aaron Laviana:

Go somewhere with experience where they do these cases. They understand the ins and outs. Don't expect just 800% smooth ride that you're going to get this done and it's going to be gravy and there's going to be no complications or no issues. I mean, both our panelist here had to undergo some revisions and changes and that's... I would almost say is more normal than not, but just understanding that things will happen along the way. You can't predict them, but there's solutions to all of it to get a great outcome. And if you can roll with that and then understanding, you're going to have to catheterize the rest of your life and having a great concept of what that actually entails. I do find sometimes that not everyone grasps that fully. And so I like to have patients basically even catheterized before, just so they understand what the actual motion is and what it is, even though it's different in your abdomen versus elsewhere. But just to kind of get a sense of, okay, this something I can do.

Morgan Stout:

Absolutely. I want to thank everybody so much for their time. Have a great night!

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