



Patient Experience with Indiana Pouches

Morgan Stout:

Perfect. I see some of our long time owners of the Indiana Pouch are already putting some questions in. So I know we're going to have a great conversation later, but until then we'll ask our patient advocates about their experience. We'll start with Cindy and then we will ask Scott about his experience. So Cindy, what is it like to go through that surgery and to be on the other side and what's it like to live daily with an Indiana Pouch?

Cindy B.:

Well, from all the trouble I had with my bladder beforehand, it's heavenly to have the Indiana Pouch. I had had so many bladder surgeries up till when I got this and I got the Indiana Pouch in 2007. And so this was like an answer to a prayer for me. It was hard, I will say the one thing I was not aware of was the fact that they took that valve and used that for my bladder, nobody told me that. So I ended up with diarrhea for years until some GI guy said, oh, I know what your problem is, you don't have that. Let's put you on a medication for that and then it's worked fine since then, so that was a nice relief.

Cindy B.:

I don't actually have the catheter. I mean, I don't have to irrigate much anymore because, probably because I've had it so long and the mucus is actually thin enough that it comes through the catheter, it just blows right out. What else... Let's see, I did have a parastomal hernia and they had to go in and remove that hernia. In the process they put mesh in and that was done in, that was probably three... No, that was in 2008, so it was a year later. So I had that until two, three years ago I think is when I ended up, hold on... I can tell you for sure.

Cindy B.:

I ended up going back into, it was all done originally in Houston with Dr. Timothy Boone and then he stepped back from practicing. So I ended up back in San Antonio with Dr. Stephen Kraus. So about three years ago, I had such bad infection from the mesh that they had to go in and move it from the right side to the left side. So that was kind of new for them because he said, well, I don't know. I've never moved anybody's from the right to the left. I don't know if it's going to work. It works great, it's just funny because I was used to catheterizing over here now I'm catheterizing over there, but it works great. I

don't get many infections, at least I'm not aware of any. I don't have any feeling to tell me when it needs to be emptied. When it was on the right side, I would have pressure on a scar that was in my stomach from a stomach tube that Dr. Boone had put in and left in so long.

Cindy B.:

I'd have pressure there and that would hurt. But now with it on the left side, I have no idea. So I just make sure I go every four to six hours. One nice thing I will say about it is if we're going to go somewhere, I will tell my husband, wait a minute, I'm going to go buy myself six hours and I'll just go to the bathroom catheterized before we leave the house. So I've bought myself six more hours, but at night I go to bed usually about midnight, I get up at six in the morning, catheterized. Sometimes I'll sleep a little bit later, but it's when I haven't had a whole lot to drink the night before and so I know that it's going to hold it and I can go sometimes eight hours. Other than that, I can't... I mean, there are times where it gets difficult to put the catheter in, but then I just sit back and tell myself to relax and get everything relaxed and then it passes in very easily. I do have another hernia over by this one now, but it's not causing me any trouble. So we aren't doing anything about it. I've helped a couple other patients. I've had people that Dr. Kraus and Dr. Boone both asked me if I would help be an advocate for patients that were going to have one and talk to them. So I even went down to Corpus Christi one time to meet a lady that was going to have one and we still contact each other.

Morgan Stout:

Well, thank you Cindy. And that's so great and it's great that you made a friend out of this as well.

Cindy B.:

It is.

Morgan Stout:

Scott, do you want to tell us a little bit about your experience, what it was like to go through that surgery and what your daily life is like now that you have an Indian Pouch?

Scott R.:

Certainly. My history was I'd actually had prostate cancer, high grade noninvasive over eight years ago with a robotic surgery done at UCLA. I did have a slight involvement with my urethra. So three years later I did develop bladder cancer, again, high grade non-invasive. My options were limited for a neobladder, the possibility was there, but I was recommended that for potential for me to really be almost cancer free for the rest of my life, the Indiana Pouch was going to be the best option where the neobladder, because of the minor involvement of my urethra was that it could come back and they do their best to get it out. So I didn't really give it much thought. And when you're dealing with the types of physicians I was dealing with, I put them in... They were part of the major decision. So that's why I ended up with an Indiana Pouch.

Scott R.:

I'm five years last March, and other than two revisions, one under general and a minor one just to get rid of some scar tissue around my stoma, I've been pretty incident free. Scans show no evidence of recurrence or anything like that. Prior to surgery, I was in very good shape, I ski, I play tennis, I work out so, and that's one thing I always stress to people when BCAN has me talked to somebody, is get in as good as shape before your surgery as possible. Exercise wise, nutritionally, emotionally and it really

makes a big difference. I found that my patch for the first year, maybe not quite year, six months, I was probably catheterizing every two hours, maybe three hours at night, depending on if I drank fluids much after 7:30.

Scott R.:

And I did wear some depends for a month or two and slept on a tux or chucks, I guess they call them at night for the first few months. Now after five years, and it would be a good question for Dr. Laviana to respond to, whether or not I can experience any more expansion. I'm now catheterizing because I'm very active exercising during the day and drinking fluids three hours. Last night, I slept six hours uninterrupted before I had to get up at six o'clock in the morning to catheterize. I feel not pain, but discomfort when it's time to catheterize. UTI wise, maybe once, twice a year, I may have to go on some particular antibiotic, but you know, if you go get a urine analysis, you're going to show that you got an infection, but normally I don't even need an RX to clear that up.

Scott R.:

The irrigation that Dr. Laviana talked about is very important. If I know if I go about two or three days without irrigating, my mucus, even after five years, will increase. But if I'm irrigating every day, I seldom see much mucus at all. So I think that's really, really important. I use a red coude 14 French catheter, which works really well for me. Coude as a little bend in the tip makes it very easy. And I also find removing the catheter too quickly, usually does lead pockets of urine. So I try to be slow and I also move a little bit side to side to try to get those pockets taken care of. There's a certain product you'll find that you use if you're very active, I happen to use one product that's a stoma cover that can contain over 25cc of leakage. And I do get leakage occasionally, if I've been drinking a lot of liquids, particularly water, I don't drink alcohol. I don't smoke cigarettes and I've always been on a very healthy diet, but again you're going to catheterize based upon how much fluid you intake, especially at late at night I wouldn't recommend that.

Scott R.:

If you have any specific questions, all I can tell you, my experience really hasn't changed my lifestyle at all. Five weeks out of the hospital, I was skiing top to bottom at Mammoth, Black Diamond, maybe, but mostly good intermediate runs and I felt fine. I went back to my normal activities. I do carry my packages with me in car, package being a lubricant, a stoma cover and my catheter, I've got three or four packages in my car and I always have one with me when I'm going out at night because you just want to be comfortable and be confident that, hey, I can deal with this very quickly and so on. So, maybe I'm not the norm, I don't know, but it hasn't been a bad experience and lifestyle wise, it hasn't made too much of an impact on how I go through my day to day activities. If there's anything else I can add, I'm happy to answer any questions, but don't be afraid just get into shape, get nutritionally responsive or responsible. And you know, most people I think will come through this very well.

Cindy B.:

Can I add a couple things, Morgan?

Morgan Stout:

Of course.

Cindy B.:

I was just thinking one thing that Dr. Laviana caught for me that no other urologist has was that I had a vitamin B12 deficiency. So I was clueless. I mean, I didn't... I just thought I was getting old and didn't want to do anything, I guess. I don't know, but he caught that for me so I was very thankful for that. I too do take catheters and everything with me everywhere I go, but keep a sense of humor. And the reason I'm going to say that is because sometimes now, my daughters now that they're older, they'll if they... If we're out somewhere together, they'll come in and if it's just them, they'll say, mom, I can tell what stall you're in and I'll say why? They'll say, because you're facing the toilet and I'll say, oh yeah, I know. You know, but it's become a thing with us to keep things on the light side. That yeah, there are differences and there are things that you can make it happy, don't make it sad. So...

Morgan Stout:

Thank you both so much. And we did have a question and if you're not comfortable answering it, Cindy and Scott, you don't have to, but it's a general question Dr. Laviana: what are the average age ranges that you can see for patients and Cindy and Scott what ages were you when you got your Indiana Pouches created?

Cindy B.:

I have to do some math with this one. I was in my fifties, but I started having bladder problems when I was in my forties. By the time I had the Indiana Pouch, I had already had eight major bladder surgeries, which just messed up my bladder to where it was no good anymore.

Scott R.:

I was 69. I'm 74 now or 68, I guess when I had the surgery and my activity level hasn't changed much. In fact, basically I'm just... I'm just voiding differently than I did before so that's how I look at it.

Morgan Stout:

And Dr. Laviana, from that medical perspective, what would you say the average age is or is there like an ideal age range for patients to get an Indiana Pouch?

Dr. Aaron Laviana:

Yeah, that's a great question. And Cindy and Scott, thank you so much for your candid answers here. I think that just provides so much insight. There is no age range, I don't look at any patient just by age alone. As Scott was alluding to, a lot of it is how healthy are you at this phase of your life? If you're active, you can walk without difficulty, if you have good control of your hands, I think that is far and away the most important thing. And if your mental status is normal and strong, then I don't think age matters as much as your overall fitness. But I would say you have to have great hand control just to be able to catheterize, unless there's someone who's going to do that for you. It's just a large burden to place on somebody else. And so I really like feeling confident that I think you can do that. And for the majority of people that's definitely possible.

Morgan Stout:

Absolutely.

Cindy B.:

All my family members knew how to irrigate it in case something ever happened and how to do it. I mean, they could have taken care of me if they had to. And by the way, my math is horrible. I was 66.

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