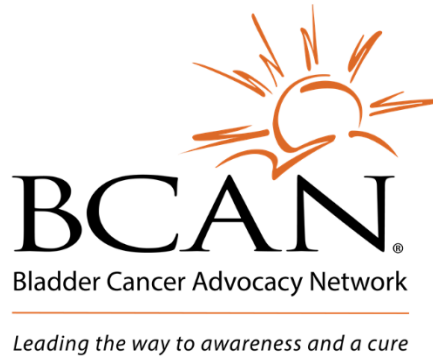


TREATMENT TALKS

What you need to
know about long term
management of
urinary diversions



The Patient Experience With Long Term Diversion Management

Stephanie Chisolm:

So much. Thank you both, it was great. I know that there were a lot of questions and some have already been answered. I'd like to invite Eric and Linda to turn on their video at this point. We're going to get a little bit about their stories with their urinary diversions and have a little chat dialogue. Then we'll open it up for the questions that you've submitted. Again, if you have any questions, please be sure you put them in the Q&A box at the bottom. Eric, welcome. It's nice to have you here. I'm very delighted that you're willing to share your story about your neobladder. Tell us, how did you end up with a neobladder? Give us the short and simple so we have time for everybody to speak. But how did you end up with a neobladder?

Eric Notti:

Well, first it started with cancer. When I was looking into the different choices; basically there's three. There's neobladder, there's the Indiana pouch, like Linda has, and then the other urinary diversion into a bag. I was trying to consider what I want to do and how I don't want to be reminded of cancer. I felt as though that the neobladder would be more like my regular life. And it has been. That has been a tremendous onus from surviving cancer, is not to have this daily reminder. My life has come back pretty much to where it was before.

The only difference is I'm on a time clock, which is pretty natural. It's every four to no more than five hours that I have to drain the bladder. That's on a pretty much 24 hour clock. I still do the nighttime get up after about four hours of sleep, drain, and then go back to bed for the rest of the evening.

It was a decision of lifestyle and what kind of maintenance I wanted to have with it. I did look into everything. The possibility of side effects, the possibility of complications and just weighed them all together and thought that this was the best choice for myself at the time.

Stephanie Chisolm:

Great. Let's hear from Linda first and tell us, continent continuous pouches are not the most common type of a urinary diversion. How did you get to that place, Linda?

Linda Waddell:

It wasn't easy. I got a lot of information when I first talked to Dr. Pohar. Initially they were thinking that I would have just chemotherapy. That was something on the wall in my bladder. But that didn't work out because the cancer had gone into the wall of my bladder. I read the information. I actually did see about BCAN and try to find out more about and different people speaking on what their experiences were. I was fortunate enough to know some people who referred me to two people who one had a neobladder, the other person had an outside bag.

I spoke to them and I mean, they both were pretty satisfied with their procedures. The person with the outside bag had said that she had had a bowel blockage. I don't know if that was because of that, I don't know because I ended up having a bowel blockage too. But I have a niece who's a nurse and she said, "Well, Aunt Linda, I'm not a stoma nurse, but I have seen different people come in with the bags and things." She told me about the irritation, about the skin around where a bag would be attached. She said she'd seen some really severe reactions from that. I have a friend who has a bag for his bowel movement and he's had a lot of complications dealing with skin surrounding that.

Linda Waddell:

So I had a little bit of reactions from adhesives, so I guess I talked it over. But her input gave me more inclination with the Indiana pouch. Even though it was going to be a longer operation and I did have a total hysterectomy during the same operation. She was saying she thought I could handle it. She said with some patients couldn't. Then Dr. Pohar reassured me that he thought I was healthy enough and he wouldn't ever have even given that option if he didn't think I would be able to cope with that catheterization every four and a half to five hours from the stoma. And the care of the stoma to keep it clean and free of bacteria, things like that.

That's where I came up with my decision. I've been very happy with the decision. Like I said, I did have a bowel blockage and had to go back to the hospital at one point in time. But in general, I've got used to the schedule. I use my phone to remind me. I set an alarm, I put it at four and a half because sometimes you're like, "Oh, boy," and you don't just jump up and catheterize. I give a half hour time limit that if I'm in bed, like, "Okay." I'll get out and I'll do my catheterization.

I also though, have been able to feel full in my back. It lets me know that it's approaching four and a half. My body just lets me know it's approaching a time when I need to empty my bladder also.

Stephanie Chisolm:

Well, sounds like you really weighed the pros and the cons and had some guidance from your niece, who's a nurse, to help you come up with that decision to make that. You mentioned that you had a bowel blockage, but let me ask Eric, have you had any complications from your neobladder that you've had to address in the long term? You've now had your neobladder for five years.

Eric Notti:

Yeah. I'm one of probably the rare ones that never really came up with anything that would be considered a real complication. Yeah, there's the typical post operation recovery. You go through sometimes a bout of bowel problems, but that was within the first three months or so. Since that point, really nothing has come up, except for one incident which came up that I made Dr. Schuckman aware of. Is I passed blood once more and this was about a year ago. Made an appointment, brought in a sample. We did another cystoscopy just to make sure everything was okay and it was and it has never taken

place since. Really, I don't think we came up with, Dr. Schuckman, any real cause that we could find. It was just a rare occurrence.

But other than that, nothing really has come up along the way. Like Linda, when this neobladder is full, you really don't need as much a watch, as you actually do as the years go on in recovery. Or at least in my case, you actually get that feeling of pressure like your old bladder. Like, "Hey, I'm full. It's time to take care of this." It was advertised as being just a piece of your intestine and has no nerve endings to talk back to you, but evidently as it fills up, it's of course pushing against everything else and it all starts giving irritated like, "You're taking up my elbow room." Then you know and you should check your clock, check your time.

Stephanie Chisolm:

It's definitely you're living by the clock. Right, you're living by the clock.

Eric Notti:

Yeah, I do adhere to the clock, but if ever you get involved in work or something, sometimes that will be an indicator that maybe I ought to check now. Yeah, it is time.

Dr. Anne Schuckman:

Yeah, maybe I could speak to that just a little bit, Stephanie. I mean, I think one of the what I would call underrated, long term issues with any urinary diversion and I'd be interested what Dr. Pohar has to say, is the issue of sleep, honestly. We didn't address that at all in this conversation. With a neobladder, we're always telling people to get up and void in the middle of the night. Or with an Indiana pouch, normally we're asking people to get up and catheterize one time in the middle of the night. Even with a conduit, patients have the most ingenious things that they come up with to be able to put their urine bag in the right place by the bed. I have patients who have rigged up wall suction units in their house so that the bag stays empty.

But I do think thinking about sleep is a huge thing that patients could consider prior to surgery. What are you willing to be doing long term in the middle of the night? I talk a lot about that, particularly with patients who are having an Indiana pouch, because I mean, you have to get up and catheterize once. I know really long term, some people don't because the pouches get big. But in the short term, for sure. And that lack of sleep can be a pretty serious factor for some patients.

Stephanie Chisolm:

Yeah, I know a lot of patients I speak to because that's the most common. The ileal conduit is the most common type of diversion that people end up with. That is a big consideration for a lot of people in terms of their lifestyle. They think, "I just want to be able to sleep through the night again." There are lots of different devices that you can use to enable you to get a good night's sleep and not have to get up. That little pouch can only go so far because it is made of intestines.

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