

Choosing your Best Urinary Diversion

For Women

Dr. Armine Smith



Stephanie Chisolm:

So what I'm going to do first is let our Survivor to Survivor volunteers, these wonderful patient advocates, speak about their various diversions first, because I think that will stimulate a few more questions. We've got a number of questions already. But I am going to actually start with Anita, if you don't mind, because you have the most common type of urinary diversion. So Anita, why don't you turn on your microphone and then talk a little bit about the factors that led you to have an ileal conduit.

Anita Cunningham:

Okay, so I'm only two years out from my bladder cancer surgery, so I am part of the organ sparing surgery that Dr. Smith was talking about. My decision to go with ileal conduit I think was mainly because I didn't want to have to catheter, I didn't want to have to deal with the supplies of cathetering. I liked being able to see the urine and know that if it becomes infected, I will immediately see it and I don't have to wait for a symptom. I'm very touchy-feely about that. I mean, when I first heard that I had bladder cancer, my first thought was get it out, just remove it. The doctor said, "Well, you're a little young and we should try some other things to do." So he had me do the BCG, which didn't work. I ended up with a T1 when I was diagnosed and then I ran into a T2 and then we decided to take it. So my choice for the ileal conduit was also something that I made the decision with a fellow bladder to bladder, or what am I saying?

Stephanie Chisolm:

Survivor to Survivor

Anita Cunningham:

Thank you. Survivor to Survivor person that I spoke with, which was super helpful. And we talked about the different diversions and I think I felt just more comfortable with this. I realized that I'm not getting away from the supplies. I still have to buy the, they call them an appliance. I still have to have the appliance. I'm wearing a bag on the outside. Anybody who knows me will always say, "I would never know. I can't see it. I would never know that you're wearing this." So it hasn't been an issue as far as that. Is there

a bump on my stomach? Yes. I don't have a flat stomach, but I think at 61 I would not expect to have a flat stomach, so I'm okay with that.

As far as the leaks and the different things that kind of come along with the ileal conduit, I think some of that is getting used to it and making your mistakes along the way and deciding, okay, if I would've done this, I wouldn't have had this leak. Some of it is about me playing this mental game of how long can I wear the appliance and find out what that is. Then I wake up to a leak. So a lot of this is self-inflicted more than it is a problem with the medical supplies. It's very easy. I come down with the system about every five days. I change it. I do it in the shower. It takes me all of about five minutes if that, to remove it, to dry myself off, to put it back on, and I'm ready to go. I've had one problem when I was out in public so far, and I literally just went in the bathroom, changed it, and I came back out and it was fine.

It's all those firsts that you have to get through to realize that life will go on and everything's going to be okay. And speaking about life, I am back to being super active. I just played two hours of pickleball today. I can go back to lifting weights. I am watching my grandbabies, I'm running around and chasing them. I went on a couple of bike trips over in Europe and I was able to ride the bike and do that. So I think life will get back to what your normal is and it's good. I'm sorry if you hear this, I've got some construction going.

Stephanie Chisolm:

We're good. We can't hear it.

Anita Cunningham:

Okay. And I think that overall this has been a very good decision for me. Is there any questions that might help me guide any further information for this?

Stephanie Chisolm:

Well, let's see if we have any questions, but Dr. Smith, when you talk to your patients who've had an ileal conduit, is their story similar to Anita's?

Dr. Armine Smith:

Yeah, I think it's a very similar theme, and I think it sounds like you've done a lot of research and you've kind of came up with the right decision for yourself. Now, were there any surprises or was there anything you wish you'd known before even making this decision? Or did you feel like you had everything kind of figured out by the time you came into that.

Anita Cunningham:

I don't feel like I had anything because all of this happened during COVID. So all of the chat rooms were shut down, all of the patient, I mean the doctor-patient relationship, all of the medical places were shut down. So without the Survivor to Survivor program, I think I would've been lost, because I really got most of my information there. I found somebody to talk to. I even lost my doctor six weeks before my surgery. So it was just crazy going through COVID with that. I think I knew my personality well enough to know that I really thought that if I can catch a urinary infection early by seeing any kind of change in the urine, then that will satisfy me. That's how my brain works, and that makes me feel comfortable knowing that I can do that.

Stephanie Chisolm:

So Mary, you have the next most common type of urinary diversion. Talk about your diversion choice. What made you decide on a neobladder and what has it done for your life? How has it impacted your life?

Mary Wink:

I've had my neobladder for 12 years and everything has been going great for me. When I was diagnosed, it took them a long time. I struggled for two years before I was even diagnosed with bladder cancer. They kept saying, "It's because you're older and you're fine." And I said, "Something's not right." So after two years when they went to scan my pelvic area, they actually shot over and got the bladder and went "ooh" So they kind of found it by mistake, because they weren't even looking in that direction for me. But once I was diagnosed and had three different opinions and got into three different doctors that each one had a completely different outlook on it. I got into a doctor that did many female neobladders. So I was very comfortable with that. That was very important to me. After looking at everything, I was diagnosed as a T1 and a very aggressive cancer, and I chose not to go with the BCG, I just didn't want to go in every three months or six months and go through that.

So for me, I just wanted to try to have as normal life as I could, and the other diversions did not appeal to me. I knew the surgery was going to be tough as probably one of the longer ones to recover from. But I felt once I make it through on the other end, I'm going to be better once I make it through the other side. I chose to go with the neobladder. The things that they talk about with the neobladder, like a year ago I went in and I just googled it and it said, you're going to have this and you're going to be incontinent and you're going to have to... I went, "Oh my gosh, I never would've chosen one of these." So I think I went yet I had a lot of information from the doctor, but I wasn't familiar with BCAN, didn't have the Survivor to Survivor experience.

So I really didn't have a lot of background information other than what the doctor was saying, "You're healthy, I think you'll do fine with the neobladder." And I chose and respected that opinion, because I didn't want to go with the other diversions and came out. I am continent day and night. I really front load all my fluids, because I know how important it is to get all those fluids. When we talk to people to say how important it is, it becomes our new normal. And to go to the bathroom three, four hours, I find it easier for me, because if I go somewhere, I can go to the bathroom before I leave and I'm good for three, four hours. If you're with other people, it's like, "Oh, I got to go to the bathroom." I go, "Yeah, I'm good."

So I think what for us becomes a new normal, I now after 12 years, I really stop my fluid intake at 7:00 pm. I sleep through the night and go all night long. Just in the morning I have a full sensation and empty my bladder. Yes, it does take longer to empty your bladder, very definitely. But that has just become part of my daily regimen and what my morning is going to look like. So if I'm going somewhere, I just make sure I plan that time and it works fine for me, and I've never had to cath. When we talk about it in our meetings, I said, "I don't even know what one looks like," because I didn't have to do that. So I learned how to empty my bladder. For me, fortunately, that has all gone well, because everyone has a different story when they come out of their surgeries. We all, I think, are individuals as the doctor will attest to that as well.

Stephanie Chisolm:

Dr. Smith, is it more challenging to do a neobladder correctly in a woman than in a man, because the urethra is shorter? Is there challenges that you have to adapt to?

Dr. Armine Smith:

I think there are, just because women have less bladder cancer than men do. It's just anything in women and bladder cancer is less studied than men. As I mentioned, the organ preservation has kind of been around for a while, but hardly has ever offered in a lot of places that I know, and that also speaks to the

fact that women are a little bit underserved in that sense. Urethra is shorter in women. That is one of the reasons the continence can be a little bit more tricky in women. But at the same time, a lot of women can also deal with the incontinence with the age and bladder overactivity. So a lot of times when you bring up this conversation, they say, "Oh, I'm already having to run to the bathroom more frequently and this is not going to change things for me quite as much."

But I think one thing that is really just unclear is why some women go into urinary retention and we just don't have any answers to that. I think in men it's a little bit more easier to conceptualize and kind of see. When men usually go into urinary retention with a neobladder, there's usually a scar buildup at the area that is connected to an stomosis. In women sometimes they can have a perfectly open urethra, but they would not be able to empty the neobladder. So yeah, I think we do need more studies in women and better kind of surgical techniques in women.

Mary Wink:

And I did have a complete hysterectomy as well, because that is what they recommended 12 years ago, and I think that has changed over the course of the years that you're doing less of that. And some of them are saying, because some of those organs are going to help support that neobladder. Even since I've had mine, there's changes as you know, that you're doing more organ sparing.

Dr. Armine Smith:

Now Mary, I have a question, so what appealed about neobladder the most to you and what resources did you have besides, it sounds like you had a great three consultations and found the right person to do the surgeon were able to get all the information from your doctor? But did you have any physical therapy, pelvic floor, anything like that or is there anything else?

Mary Wink:

I didn't have any of that. My first consultation with a doctor was he came out of medical school and he had seen one done and was very confident that he could do the neobladder surgery. And we went, "Yeah, that's not going to work. We're not comfortable with that." We went to the Mayo Clinic, which you're probably familiar with, and met with two doctors there, and they came in and said, "I think you're a very good candidate for the neobladder." And this was back in October, and they said, "I think you should go home and enjoy your holidays, because your life will never be the same."

I thought, am I being punked? That just wasn't what I wanted to hear. Then I got in front of UW-Madison in Wisconsin and then got in front of a doctor who had done a lot of the female neobladders and explained everything and his team, and they actually had two teams during surgery. They had a team that came in and did the neobladder and they had a team that came in and did the hysterectomy. So there was a number of people that were on that surgery, and that just made me feel comfortable to do that. I did speak to two people that had neobladders, one that was very successful and did well, and another that she wears a diaper every night and she's okay with that, and it's like, "I'm not okay with that."

It was never recommended to have physical therapy, but I spoke with somebody and said how important it is to get yourself as strong and healthy before surgery. So I had exercised every day and really did a lot of core exercises, and I continued to do that daily. So I think that's really important is to get as healthy as you can before the surgery and get as strong as you can. So that was my going into the surgery, was to try to prepare myself and get as healthy as I could prior to, because it was going to be a little tough surgery. So that's kind of how I went in and the attitude I went into.

Stephanie Chisolm:

Well, great. Well, let's hear from our third volunteer that comes on here. She is our super BCAN of Hope from 2022, right, Karen?

Karen Godfrey:

Right, yes.

Stephanie Chisolm:

So Karen has been one of our longest volunteers. I remember meeting Karen way back early in the early years of Beacon. Karen, you have an Indiana pouch and that's not the most common type of urinary diversion, and you've had it for a while. What guided you to that decision?

Karen Godfrey:

Well, I tell everybody that my surgery was back in 2004, and that was before there was any help out there for any of us. BCAN hadn't come on the scene yet, and there was nothing from the American Cancer Society that I could learn from. So it was my surgeon that put me through the education part and the surgery and the recovery. Then also during recovery, it was, you learn by experience, because there was still nobody to talk to. So my diagnosis at the beginning was T2, muscle-invasive, and there was no protocol at that time to do chemotherapy. So I went directly to surgery within three months of my diagnosis. I tell everybody that my story is not typical, but I am so incredibly fortunate that my general practitioner just picked a urologist to send me to and my UTI that he supposed I had wasn't clearing up.

The fellow that he sent me to had really good training in Chicago. He had come back down to Florida where I lived and was with a practice that could do all three diversions. He's the one that gave me the information about the diversions. The main reason that we talked about the neobladder and the Indiana pouch was my age and my overall general health. I was still young, I had excellent health other than having muscle invasive bladder cancer. My thought at that time was whatever it takes to rid myself of the cancer is more important than the diversion. So we discussed the neobladder. My surgeon thought that my urethra might possibly be involved, so that was kind of on the table, but he wasn't certain that that would be a possibility. We talked about the Indiana pouch and we talked about the ileal conduit or the IC.

I was fine with any of the three, because not being able to really learn a lot from other people, I didn't have a lot of stories to compare with. So it was, "Okay, doctor, when you get in there, whatever you find, do what you have to do and give me what you feel like is best for me." So I did not know until I woke up from the surgery that I did have the Indiana pouch. In recovery time there was really no home health that knew a lot about the Indiana pouch. So I was kind of on my own to figure out what was happening during the recovery. I can say like Mary and Anita have said, a lot of our surgical recovery is all the same. We go through what's working, what's not working, and how we can figure out what works for us best and being very proactive in figuring out what will be the best for us.

I think I was about six weeks out before I really learned that I wasn't totally emptying my pouch each time that I catheterized, and it was because I really hadn't had good information from the nursing staff in my recovery time. I can tell you that a lot of the tips and the tricks that I have learned down through time have come from don't do as I did, but do as I've learned.

I learned early on that hydration is really key to having good function with the kidneys and with our pouches. My surgery was in '04, by '06 I was active with BCAN and by '07 and '08 we were talking to people in the local area. And by '09 we had a support group down here in Florida. I was learning with them and through them and because we've always been open to anybody and everybody, it's not Indiana pouch

people or neo people or IC people, it's everybody combined, we've learned together what works and what's best and how people have adapted. It doesn't matter what diversion you have, we can adapt to what works for us and have a really good quality of life. I've had grandchildren born since my surgery. I carried two at a time on my hips, because they were only a year apart and you pick up one and the other one wants up there too. So here I was walking around with two babies on my hips and I have not had a hernia because of that.

I feel like my life has gone on just like it was before. I just pee differently. Catheterizing is no big deal at all. I want to show you, this can fit in your sock, it can fit in your purse. It's the only thing you really need when you leave the house. But like Mary said, if I know I'm going to be out of the house, I empty before I leave. It's kind of telling the kids when we're getting ready to leave the house, "Go to the bathroom," and they'll say, "I don't need to." And we say, "Well, go anyway." So it's rare now that I need to void when I'm out in public.

In the beginning you're kind of paranoid and you're just scared to death that you're going to get somewhere and you're going to have an issue. And so you are more anxious than you really need to be. I try to tell everybody, we should not let our diversions rule us. It's just a part of who we are now, and we are the boss of our diversion. So don't let setting an alarm clock telling you what you have to do and when you have to do it. In the early stages, I would say the first year or so, those of us with the neo and the Indiana pouch probably do need to get up at night.

I see people don't, because they will have a night bag that they put on so they can sleep through the night a lot quicker than we do. But eventually you will get to the point where you can sleep through the night. I'm a night owl, so it's like 11:30 pm, midnight before I'm down for the count and I'm good to go till 6:30, seven o'clock in the morning. I drink liquids throughout the day. I don't try to lessen them as the evening comes on. As far as having good healthy blood work, that's the one thing that the doctors will be watching after your surgery is every time you have a checkup, they're going to look and see how your kidneys are functioning. I just had my 19-year checkup with my doctor a couple of weeks ago and he said, "Your blood work is perfect for you." And I have not had any issues with any kind of backflow, any kind of B12, vitamin D. I've been just a little bit low on vitamin D. But I mean, I think at my age that's probably not necessarily the Indiana pouch's problem.

B12 has been fine. So I can say that I have not had any issues with the Indiana pouch that would have made me think down the road, "Not sure that this was a good idea." Being in my early 60s when I had the surgery, I've had 20 years of living with no more than having to take a catheter in my purse with me when I go somewhere. One thing about learning how to fully empty your pouch, I believe that those of us that have gone through the surgery and we have made use of the Survivor to Survivor group prior surgery, need to stay in touch with the people that we've talked to about our diversions. Because during the recovery period, that's when you have a lot of questions that that person can help you with in trying to figure out how you're getting through the training stage, as we call it.

Learning how to empty an Indiana pouch is an art. It's not a matter of just having the catheter in and when it quits draining, you're done. I can tell you what I say, and then Dr. Smith can tell me whether or not I'm totally out of the ballpark or not. But I envision my pouch as a water filled balloon, and if you have this balloon in your hand and you squeeze it, the water inside that balloon is going to move to another location. So when I am cathing to empty, when I get the initial stop on the catheterization, I press on my tummy and or jostle my tummy to hopefully move any urine that might still be in the pouch to another location so that the catheter finds it. And nine times out of 10, you will get quite a bit more by doing that.

So I think that is one of the healthy things that I've been able to do over the years. Then also, because our patches will produce mucus, it gets less during the ensuing years. But if you let up on your high hydration, you will see an increase in the mucus. You don't want to be clumpy looking. So envisioning this water fill

balloon again, I'm thinking if as the balloon collapses down on itself as the water is emptied or the urine is emptied out of the balloon, some mucus can get trapped into a pocket or a little corner of this pouch. So if you're not staying well hydrated, that little bit of mucus can get stuck there. And that's where you would start growing a bladder stone. So if you're really hyper on doing your liquids and if you work to consistently empty the pouch every time that you go to make sure that you're fully emptying, you'll have a healthy pouch. I'm sure that there's a lot of questions with what I just said, so we'll wait and see what everybody asks.

Dr. Armine Smith:

I do have one question now. Did you have to modify your diet in any kind of way for the mucus production or the hydration is kind of all you've done?

Karen Godfrey:

One thing that I have always done is I've always had citrus in my drinks and I do drink cranberry juice and stuff like that too, but I have felt over the years that the citrus has made a difference in my pouch. Some people think that milk products will make more mucus and I'm not sure, because I've never noticed a big difference. But it could be the difference in people's digestive systems too.

Dr. Armine Smith:

Yeah, no, that makes sense. I'm so glad you brought up kind of the abdominal musculature, because I think we forget that there are a few different ways to empty the bladder or neobladder or pouch. And abdominal muscles also create pressure, and a lot of people with the neobladders kind of end up urinating that way, just putting some pressure on the abdominal muscles and trying to get the bladder. And now with the Indiana pouch, I haven't heard that actually. I think it's a really great point for people to know. That you can use this Valsalva or the abdominal muscles to get the pouch to squeeze a little bit better.

Stephanie Chisolm:

So this has been wonderful. I know that one of the common threads that I noted on my page over here is many of you went for a while before your initial diagnosis. So Dr. Smith, I know that that seems to be a trend for women in particular, because when they have any of the signs and symptoms of bladder cancer, the urgency or frequency, they typically occur with aging. And even in the case of hematuria, if they don't go to a urologist first, they often will have a delay in their diagnosis. And for some it can be a couple of years as we've just heard. So do you see that frequently that many women, by the time they get to you, have already gone through multiple rounds of perhaps antibiotics for urinary tract infections, because nobody saw that they had bladder cancer? Is that a common thing?

Dr. Armine Smith:

Yeah, that's 100% true. I feel that is very common for a woman to have at least a couple of diagnoses of UTI before ending up with the urologist. I think some things that are different in women versus men, men freaked out when they see a drop of blood in the urine. Women for them, for us, it's not quite as different as having the menses. So you don't just run to the urologist. A lot of people end up in the minute clinics and they get a course of antibiotic, and then symptoms continue. Blood continues, they go get another one, and then for a while, and then they're like, "Something's not right." Then they end up with the urologist. Very common story with women. It's very widely known that there's a delay in diagnose of

women and then some women are diagnosed in a later stage just because one of the reasons being the delayed diagnosis. Yes.

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