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**Stephanie Chisolm:**

Great. Well, let me go to some questions from the participants. "Typically, how long does one need to use a catheter after neobladder surgery? I know it takes time to train a neobladder and for the person to learn really how to forcefully push that urine out internally." This is a good question for Dr. Poch, so what's sort of the average length of time post neobladder surgery that somebody needs to catheterize?

**Dr. Poch:**

It's a great question. It's something that comes up frequently. Normally when we do neobladder, we typically will leave the catheter in for about three weeks, so patients will go home with a catheter. After that three week period, we then remove the catheter and then we ask patients to start cathing and then keep a log, and that log really tells us how well patients are emptying. What we have patients do is basically pee in the toilet and then catheterize afterwards to see how much urine is coming out. Now, it doesn't have to be after every single catheterization, but we ask them to do it once or twice at least per day. We usually do it for the first month and then we usually then we'll start either tapering that off or readjusting frequency of catheterization, depending upon what some of those numbers look like. Because if patients are doing great, then we sort of taper that off pretty quickly.

We do often have patients that we don't see for years. They come back, they get discharged and they still carry pretty large residuals of urine and need to go back and start catheterizing once maybe a week or every other day just to get the neobladder to contract a little bit. There is that risk of if you miss some of those followups, that we don't get a good sense of "Are you really emptying?" But we try to taper it off after about a month to six weeks depending upon how patients are doing.

**Stephanie Chisolm:**

There are things that people can do, like staying hydrated to help with any kind of... Again, thinking that the neobladder's made out of intestines, which typically have mucus and that can clog sometimes. Are there tips that you can offer to patients who have a neobladder to help keep it healthy and keep it flowing when they want it to and when it doesn't?

**Dr. Poch:**

Yeah, so I think, as you mentioned, hydration is key. I think that the intestinal diversions and even patients with conduits will see this. They'll get mucus that sort of gets built up. Over time that usually

depletes or decreases. It never goes away altogether, but that mucus puts you at risk for developing stones and can clog and some other issues. It's always important to stay very well hydrated if you've got these urinary diversions. That also helps with the smell, so a lot of patients will have a concentrated urine smell. They say, "Well, I think I've got an infection," when it's really just really concentrated urine. Some of the malodors and those kinds of things are actually just better treated initially with pretty aggressive hydration.

There are some other dietary things that happen. Sometimes patients who have some milk-based foods will also have to see an increased amount of mucus production from their continent diversions or even conduits. There are some other foods that we've had patients come in and tell us, sort of unusual foods that they've had, that have initiated an increased production of mucus also. Again, each patient's a little bit different, but hydration, I think, is key.

### **Stephanie Chisolm:**

Tom, Did you have anything to add?

### **Thomas:**

Hydration is key. I love fruit. It helps. I stay away from asparagus, from the standpoint of smell. But I had my surgery in October, early October. I spent 30 days at Houston until they removed the tubes, came back to Georgia. I went back in November for a followup. I cathed that November, December, January. I cath once a month, just my own desire to do so. Of course, there is mucus production, but the more you drink of water or with lemon, any type of citrus in it, the better off you're going to be, or I have found that you will dilute it and you're not faced with the smell or residue as much as you would be without drinking fluids often. Other than that, do I cath every week? No, I just cath once a month, my own routine just as a wellness cath, and very happy with that.

### **Stephanie Chisolm:**

Kind of making sure that any residual urine, as Dr. Poch was explaining, is emptied out, so that's important. This is good. There's still a lot that you have to do for maintenance on even the neobladder or anything where you think you're going back to sort of living a normal life. But let's talk another question that's not really related to this particular topic. If upper tract disease is involved and you're having one kidney removed with no evidence of disease in the remaining kidney, would a neobladder be an option, Dr. Poch? Because the neobladder's connected with the two ureters from the kidneys.

### **Dr. Poch:**

It's still an option, but it really depends on what the overall kidney function is going to be. Obviously, yeah, in life you've got most patients have two kidneys. If you have to remove one of the kidneys that can affect your overall kidney function. Patients can still be candidates for neobladders, but it really depends on what we think the baseline kidney function is, and if it's not great to start out with, then we know it's going to get worse after surgery to remove one of the kidneys, that may sort of hit that tipping point of that creatinine level, which is that blood test to measure kidney function. If we think that that's going to end up going over 2.0, then we may be a little bit reluctant to do a continent diversion, but it sort of depends on what the baseline kidney function is.

Then nothing is ever identical in life, so sometimes one kidney's working better than the other kidney, so the kidney with cancer and it actually may not be as functional as the kidney without cancer, so it depends on some of those other factors about how does the function of each individual kidney look, and

there's certain tests that you can do to actually assess how one kidney's working versus the other as well.

### **Stephanie Chisolm:**

Great. That's wonderful. I'm sorry, my lights just turned off, so I was just trying to open my shades a little bit, so I'll put my camera back on. Another question. If somebody had their prostate removed and they didn't have radiation, not having a prostate, is that an issue if they were going with the neobladder choice? It doesn't have radiation to cause that scarring, but if you didn't know where the prostate... Is it different if the prostate's already been removed?

### **Dr. Poch:**

Yeah, I mean, the operation can be a little bit more technically challenging because you're just doing an operation in the same area where somebody's had an operation before. I would counsel patients that there's always a possibility that the tissues don't look healthy enough or that urethra doesn't look healthy enough to attach a neobladder to. I usually tell patients it's sort of a game time decision in terms of what we think the quality of the tissues will be involved, will the neobladder heal? We more strongly make sure that we have the appropriate second choice for urinary diversion chosen in case we end up in a problem where we can't do it.

### **Stephanie Chisolm:**

Okay, so you've got a plan B in place, so that's good. In terms of when you're looking at voiding, emptying your bladder with a neobladder, you're obviously using different muscles to bear down and empty the bladder. When you're making a referral maybe to a pelvic floor physical therapist, Dr. Poch, is that what you typically will do to help somebody to learn how to control those muscles, to be able to void through their urethra when they don't have the same mechanisms, the same urge to go to the bathroom that they would with the neobladder?

### **Stephanie Chisolm:**

We do frequently employ a physical therapist that do pelvic floor therapy. Most of the time it's not actually, at least in my experience, it's not for those patients to help them go, but it's sort of for patients that have some incontinence risk or have some leakage of their pelvic floor and they don't really understand or can't get down Kegel exercises, which are those pelvic floor strengthening exercises that you do, typically to try to keep the urine in or maintain urinary control. We typically will have patients sent to physical therapists. They'll actually do something called biofeedback where they put little sensors in around your pelvic area and to see how well you're contracting, because you may think you're doing it right and you're not. They help determine what muscles you need to contract and try to reteach you how to contract some of your pelvic floor muscles.

Most of the patients that we have who have neobladders and will void either spontaneous or doing a Credé maneuver, which is sort of pushing above your pubic bone to try to help get the urine out. Maybe Thomas can sort of elaborate about his personal experiences. Most of the studies in our patient populations here actually have a pretty good rate of urinary control and emptying. Most of the urinary leakage that happens usually happens at nighttime when the brain falls asleep and the pelvic floor falls asleep together and that's typically when people end up having some leakage.

### **Thomas:**

Yep.

### **Stephanie Chisolm:**

Just "Yep?" You got anything else, Thomas? Did you go through physical therapy?

### **Thomas:**

I went to a physical therapist and they told me key is your core. They gave me a number of exercises to strengthen my Kegel, do Kegel exercises. During the daytime I'm fine. I void once every three hours. At nighttime, I set my clock for 1:00, 4:00 and 6:00, and I get up and I void at that time. Depending on how much fluids I have had at dinner and after dinner, I may wear Depends at night, just in the event I have some leakage. But I have learned to control it during the daytime, and working on the evening, but hey, getting up with an alarm clock is not the end of the world. So far, so good in my arena.

### **Jonathan:**

It's just another advantage of the ileal conduit. I go to bed about... Well, I go to sleep about 7:00, then I get up and go to bed about 11:00 [inaudible 00:56:18]. I just set my alarm for 7:00 and get up at 7:00. When you have the ileal conduit, you don't have to get up at night at all. You just get to sleep through the night, except for normal old man getting up stuff at 4:00 and wandering around the house. But there's no need to get up. On a serious note, that helps with the hydration situation. When you have any diversion, there's an increased opportunity for infections, bladder infections, and the flushing out seems to help a lot. So I can hydrate as much as I want to without any fear of having to over-hydrate and have to go to the bathroom too much.

### **Stephanie Chisolm:**

Yeah. At night, Jonathan, do you use a leg bag? Not a leg bag, I mean a night bag or a bigger container for catching all that urine so you don't have to worry about that small bag that you held up filling up too much?

### **Jonathan:**

Yeah, you can't keep your daytime bag on. It'll fill up too quickly. When I was in the hospital, they gave me a Bard medical bag and that's just kind of the basic thing, and I just stayed with that. Yeah, you attach it to the bottom of your pouch and just hang it over the edge of the bed. Some people put it in a trash can. There's all kind of ways to help it. All you have to worry about is turning over too quickly or getting the tube wrapped around your leg, and if you do that, you have a complete mess on your hands. But the people that I talk to that have an ileal conduit all end up sleeping differently, and I'm talking about mentally sleeping. You actually are kind of, even though you're dead asleep, you have the knowledge that you've got this tube hanging out and you learn not to flip over too quickly or whatever. But I don't have to sleep on my back or my side or anything. I sleep all positions.

### **Dr. Poch:**

One of the hacks that we just learned about this in clinic was one of our patients was taking a wire hanger and putting it in between the mattress and the box spring and they were sort of sticking it out sideways and they were hanging their bag on that rather than using the trash can, but allow gravity to flow. I thought that was a cool hack.

### **Jonathan:**

Yeah.

**Stephanie Chisolm:**

Yeah, there's lots of great tricks.

**Jonathan:**

All kind of things that you learn how to do that you've never anticipated learning how to do.

**Thomas:**

No.

**Stephanie Chisolm:**

Sure, that's very true. We do have another question, and I know you can probably just talk on it briefly because it was what you talked about in terms of removing the prostate. You asked a question earlier, Dr. Poch, about sexual health questions, and we have a whole bunch of resources if anybody is looking. If you go to the... I'll put it in the chat so that... Let's see if I can get it in here in the chat. We have a lot of resources including videos about sexual health, but there was a question about, "Does removing the prostate impact sexual health?" And that includes every type of a diversion. Can you just briefly touch on that knowing that we have other webinars? I dropped the link in there for everybody.

**Dr. Poch:**

The bottom line is yes, and we talk about this with our prostate cancer patients too. The nerves that provide sexual function to the penis basically sit on top of the prostate. Anytime you're operating in and around the prostate, there's always risk of injuring those nerves or you purposely remove the nerves depending upon sort of cancer status. One of the big challenges in urology in general is sort of managing sexual function in and around removal of pelvic organs. There are ways to do nerve sparing, radical cystoprostatectomy, so you can do a nerve sparing operation just like we would do when we do prostate removals, if the patients are appropriate candidates, to try to preserve sexual function. I would say that it really depends on the tumor location and the involvement, but I think it's an important thing to bring up with the physician that's treating you saying, "These are my priorities."

When we go through a priority list, we say, "Okay, well, how important is sexual function on your priority list?" That's a hard conversation to have, and it's hard to sort of tease out. Sometimes patients are not as forthcoming with that information or they don't want to say because they're worried about cancer diagnosis and it's sort of taking a second back burner. But once you manage cancer, you don't want to sort of leave a path of destruction, and including sexual function, if you can avoid it two, three or four years down the road. I think it's important to address and bring up and have those conversations.

**Stephanie Chisolm:**

Sure.

**Jonathan:**

I think y'all kind of dance around about that. On an S to S call, after we exchange pleasantries and all that, the next thing they want to know is, "Can I have sex?" Whether they tell you, Doctor, that that's important to them or not, it probably is. I had a prostatectomy before I had my radical cystectomy. I would encourage you to go to the website. There are many, many, many things that you can do to achieve sexual health and most of them work. I'm 72 years old. I still have a very active sex life with my

wife, and there's things that can be done, but clinicians tend to kind of dance around it. When you ask directly, "What's my sex life going to be like?" They say, "Well, how important is that to you?" It's important, and so that's one of the things that we exchange, and I think that's one of the values of the S to S program is you can ask a guy a blunt question and get a blunt answer.

### **Stephanie Chisolm:**

I did put the link to some of the physical and psychosocial sexual health after bladder cancer. It's one of the many webinars that we have archived on our website. There are, as you said, tons of resources, and I think it often is, "You saved my life." But without really thinking about the sexual function part of it, that people get a little upset that you took away some of the good parts. That's an important conversation, but not every patient is comfortable bringing that out, and not every doctor is comfortable bringing it up either. It's unfortunately going to be on the patients to be a little bit more proactive in asking questions specific to that. There's never guarantees, but certainly there's things that skilled doctors can do to help preserve sexual function or there's ways that they can help enhance that for after the surgery as well. Great topic, and that was a good question. Thank you for asking it. Couple more questions. Is there much downside in a six month or so delay for having your bladder removed to try alternative immunotherapy or chemotherapy treatments, in general? That's a good general question.

### **Dr. Poch:**

Oh, there's a tricky question. For muscle invasive bladder cancers, there's some studies to suggest you shouldn't delay treatment at all, whether that's starting chemo or getting a cystectomy because that can affect overall mortality. Certainly trying alternative therapies for muscle invasive bladder cancer is a little bit risky. We get this a lot with patients with stage one bladder cancers who've gone through BCG therapy and then are considering alternative therapy, whether that's in bladder chemo, clinical trial, something else. The answer is we don't know. We don't what that runway is before it becomes more risky in terms of either progression to muscle invasive bladder cancer or developing metastatic cancer into the lymph nodes, even with stage one disease, because that can happen.

If you look at some of the studies, about 5% of men or 5% of patients, I would say, that end up having their bladders removed with still stage one disease because they failed other treatments may have some microscopic cancer in their lymph nodes. There is a runway there. We usually think it's about a year to 18 months worth of trying other things for patients that have failed traditional therapies in the bladder. But we don't really know the right answer to that, to be honest.

### **Stephanie Chisolm:**

Right. You do look at the pathology to see how aggressive that tumor looks too, right?

### **Dr. Poch:**

Right.

### **Stephanie Chisolm:**

You're looking at all of the big picture, so it's very individual. Would it be wise to talk about being in the clinical trial? Because you're being observed, you're getting an opportunity to try something that might have benefit, but you're also getting a lot of observation. I know you do a lot of clinical trials down there at Moffitt.

### **Dr. Poch:**

Yeah, I mean, I think clinical trials in the post-BCG treatment space is very important because obviously based upon all the discussions that we've had here, some patients have muscle based bladder cancer, but some people undergo cystectomy because none of the other treatments work for their stage one cancers. I think it's important to consider what are other options for those patients because functionally they don't want to keep their bladders, they don't have as high risk tumor as your Stage 2s, so I think clinical trials are really important in this space. One of the challenges that we've had recently, a lot of the inclusion criteria are fairly strict for clinical trials in terms of having received prior BCG.

With the BCG shortage, which most people are familiar with, it's made a little bit of a challenge trying to hit all the boxes to enroll patients in clinical trials because of that shortage. There's some adjustments that a lot of the clinical trials are undergoing right now, including the one that we've got in Moffitt, to try to expand what that definition of patients is so that they can be enrolled in some of these trials.

### **Stephanie Chisolm:**

Okay. Technical question. Patient is thinking of an ileal conduit as their choice of diversion, however they're overweight. What kind of issue is that?

### **Dr. Poch:**

I think the ileal conduit is a great first start. I think it really depends on, as I said, the abdominal wall and what the abdominal wall looks like in the body habitus. Overweight comes in a lot of different shapes and sizes and where that fat's located, and is it body fat, leg fat, how thick is the abdominal wall, some of those things that we can see on CT scan? Again, it's an individualized approach. Usually, according to most of the textbooks, and what we do when we do our board exams, is ileal conduit should be a default or can be a default because there's very few reasons not to do it.

### **Stephanie Chisolm:**

Okay. Any other comments there? I have two more questions that I wanted to get to today, and this is... Nope. Okay. "Are diversion options reversible? Maybe you start with one. Can you switch to another? How often does that occur and is it even possible to maybe get an ileal conduit and then decide you're going to get a neobladder, vice versa?"

### **Dr. Poch:**

It's pretty hard. The human body only has so much intestine to work with and it can be pretty challenging. It'd be interesting to know from the group here, most patients initially after surgery will have some trouble with being regular in terms of their bowel function, whether that's too much or too little or yo-yoing back and forth. The more bowel you take to do your different diversions, the more challenging it can be, and nobody really wants to do redo operations to do that, so I would say it's pretty unusual. There are some patients who end up having urethral recurrences after neobladders, for example, who then you need to sort of manage by removing their neobladder and their urethra, so that can happen.

I didn't go to specifically about the different types of urinary diversions in terms of neobladder and there's couple technical differences between a couple of the neobladders, but you can convert one of the neobladders to a conduit without much trouble. The other neobladder, which is the one that I do, I actually just remove the whole neobladder, and if we're going to do a conduit, we'll just take a separate section of intestine to do that. It can happen, but it's unlikely, and not recommended.

### **Stephanie Chisolm:**

Okay. Well yeah, this has been fabulous. Last question, "Did any of you go through chemotherapy prior to having your bladder removed?"

**Thomas:**

Yes.

**Denver:**

I did not.

**Jonathan:**

Yes.

**Stephanie Chisolm:**

Okay. Two yeses and a no. So how common is going through what we call neoadjuvant chemotherapy before you do that surgery? Is that something that's routinely done by most doctors?

**Dr. Poch:**

For patients with muscle invasive bladder cancer, it's right now giving chemotherapy is considered standard of care prior to doing surgery to remove the bladder. That being said, that's based upon some clinical trials that were done and showing an improved survival and downstaging of tumors. There are some indications where you wouldn't give chemotherapy upfront, mostly based upon kidney function. If patients have poor kidney function, then one of the drugs that's frequently used is a drug called cisplatin, that's that drug can be toxic to the kidneys. So if we can't give that drug prior to surgery, then a lot of times patients are just going to move straight to surgery. If you look at the population based data, we're getting better. I think that number's probably around 40 to 50% of patients are getting chemotherapy prior to surgery, not just because they're not being recommended for it, but there are some other clinical factors. We talked about the performance status and kidney function would be two reasons, maybe not.

**Stephanie Chisolm:**

Right. Well, I hope everybody that's been on this call with us, and there are quite a few people that were here, really got something out of it. If nothing else, you maybe got some questions that you should ask your doctors, because that dialogue needs to start somewhere. If your doctor doesn't bring up these shared decisions, maybe you should bring them up and tell them what's important to you as you're facing the potential for bladder removal surgery.



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