

## **Stephanie Chisolm:**

Thank you so much, Dr. Mossanen. That was fabulous and really nicely done. A great explanation of the various procedures. And we do have a number of questions, but I thought of a couple too while I was listening to you. So do you have a preference? Are you a robotic surgeon or an open surgeon?

#### Dr. Matthew Mossanen:

That's a good question. I kind of do it on availability, where I have the next available slot. Patients will often ask me what the main differences are. Open surgery might be a little bit quicker, robotic surgery might be a little bit longer, but have less blood loss. I like open surgery, it's how I was trained. I also enjoy robotic surgery, so I think I'm mixed on it. I think the previous generation was all open surgeons. I think the upcoming generation is going to be mostly robotic surgeons, so we'll see how the story unfolds. But the good news for patients just to emphasize is it's probably equivalent. They're probably both good. It's more about the person doing the cutting and sewing than the tools they're using.

## Stephanie Chisolm:

Sure, absolutely. I always sort of joke and say, well, if you're Jaguar had an issue, you wouldn't take it to the mechanic on the corner. You would take it to the Jaguar dealer that does this all the time. And we need to make sure that we take good care of our health and go to the right people. So we had a bunch of excellent questions. I'm really interested in the difference, if any, between a radical cystectomy neobladder surgery between men and women. The question was about whether women have more problems than men do. Is there an issue with that in terms of gender?

## Dr. Matthew Mossanen:

One of the complications that can happen after a female neobladder surgery is that the neobladder could form a fistula with the vagina. And so the woman could have leakage of urine through the vaginal canal, and that's a really serious problem.

For male patients, it's not very common to have leakage into any of the adjacent structures. And so you could say that women might be at risk for something more significant because the vagina is near that location. Some surgeons might do vaginal sparing to avoid any possibility of forming a connection between a hole in the vagina that's getting sewn and a hole in the neobladder that's getting sewn.

## Stephanie Chisolm:

Sure. So if somebody, say a woman, wanted to also preserve sexual function, nerve sparing would be important as well for women. And then she should speak to her doctor about just how much of the vagina might need to be altered because of this.

## Dr. Matthew Mossanen:

So you can remove part of the vagina or you can... And that would be the anterior wall. So when we say that, it's that the bladder is sitting on top of the vagina, so when you take out the bladder, you're also removing a strip of the vagina and then folding it closed or sewing it closed. So in some cases, rather than remove the roof of the vagina, you can actually just leave it intact and take out the bladder. But it depends on tumor features, prior surgery, patient preferences, but that's something that can be considered with cystectomy.

## Stephanie Chisolm:

Okay. And then it's also, would you comment a little bit in terms of when patients who do, excuse me, have their bladder removed for females, if they had issues later on with sexuality and sexual function with intercourse, what would you recommend to them? How would they go and get therapy?

## Dr. Matthew Mossanen:

I have patients that I've sent to pelvic floor physical therapy before and they've found it very helpful. I'm also fortunate enough to work with a very skilled PA that has a lot of experience with cystectomy patients and she's a valuable resource to them. So the combination of those two things and then case by case basis, we figure out what the patient needs.

I do try to make sure that any female patient and also male patients, that they know they can talk to another patient that's gone through all this because I have found that it's sometimes helpful to talk to somebody who has lived it. And so I think BCAN has lots of opportunities for that. But I also have a small group of patients that are always willing to talk to other patients over the years.

# Stephanie Chisolm:

Right. Our Survivor to Survivor program can help connect you to somebody who has the type of diversion you're considering. So I definitely encourage you to visit bcan.org and look for the Survivor to Survivor program if you're interested in doing something like that. I have dropped a couple of links in the chat feature to some of the additional resources that we do have available about cystectomy. So let me go back to the questions that were submitted.

"I was treated at Brigham and Women's and had a cystectomy two years ago and doing very well. I'm grateful for the excellent care I received. My question is, can you speak to what are the longer-term issues post-surgery that we should be aware of? Hernias, fistulas differences as you already touched on briefly for men and women."

## Dr. Matthew Mossanen:

Yeah, hernia is always an issue for the urinary stoma. Getting a parastomal hernia or a hernia near the stoma is a problem that can be seen commonly. For the neobladders, leakage can be a problem for both men and women, and so learning to self-catheterize and often needing diapers while urinary control is sort of recovered and you relearn how to use your neobladder is common. Fistulas can happen. Strictures is also an issue that can happen where you sew in those little tubes into the piece of intestine, it can scar down and that can be an issue. Those are some of the main things that we see. I think when we talk about preservation of sexual function, an important question that we always start with is what is your baseline sexual function? For example, for a man, we'll talk about how well erections work and then go from there in order to discuss nerve sparing. I think was there another part to that question that I answered?

## Stephanie Chisolm:

No, but I think one of the things I think would probably be helpful, could you explain what a fistula is? Because I'm not sure if people haven't had one that they would know what that is. It's a complicated term that I don't know that everybody understands.

## Dr. Matthew Mossanen:

Yeah, that's a good question. So a fistula is an abnormal connection between two places. So you have a bladder that connects to the outside world, but sometimes the urine can have an abnormal tunnel to another part of the body so that urine leaks through there. And so for women after a neobladder construction, it's possible to have a fistula to the vagina, that would be an abnormal connection between those two structures.

## Stephanie Chisolm:

Okay, thank you. That was really helpful to understand. So do any patients have partial cystectomies and what's the difference between a partial or a total cystectomy or a radical cystectomy as they call it, and who would be eligible for a partial cystectomy if it's even done?

## Dr. Matthew Mossanen:

You can consider a partial cystectomy based on the anatomy of the bladder and the cancer diagnosis. For more advanced stage bladder cancers, we don't usually consider a partial cystectomy for cancer reasons. You can consider a partial cystectomy under specific situations because our concern would be that you remove a tumor, but the rest of the bladder is also at risk for cancer that can then come back or spread. So patients with cancer in a diverticulum, you could consider that for example. And a diverticulum is basically a cave in the bladder. So that's one scenario that could be discussed. But again, that's a complicated question, so I think it would depend case by case basis.

## Stephanie Chisolm:

Sure. And they're not very common?

## Dr. Matthew Mossanen:

Not very common. That's right.

## Stephanie Chisolm:

This person said, "I have my second high grade tumor in three years. My case goes to tumor board on Friday. Do you think removal of my bladder will be an option?"

## Dr. Matthew Mossanen:

It's hard to know without details on treatment and more specifics, but I think the idea is that we typically think of cystectomy in patients that have stage two or greater, which is muscle invasion, invasion of the bladder wall muscle. But that question is important because it highlights that patients which have recurrent high grade tumors, despite multiple treatments in the bladder, can also be eligible for cystectomy. And so the answer to that question is probably yes, depending on additional details, but there are a lot of alternatives to cystectomy and it's important to mention that in addition to cystectomy, you can try radiation for specific cases or other types of intravesical or inside the bladder therapies.

## Stephanie Chisolm:

All right. This next question's a little bit confusing. "What is the life expectation for each procedure?" And maybe just talk about perhaps some of the complications because I don't know that... Is there a difference between life expectancy with an ileal conduit versus a neobladder or an Indiana Pouch?

## Dr. Matthew Mossanen:

There shouldn't be. That's a really good question. There shouldn't be a difference from the urinary diversion. That's sort of a reshaping of the intestine to store and transport urine. So the main way that we determine the cancer outcome is with what was removed, what was in the bladder. So the cancer staging is what drives the ultimate outcome. In terms of complications and which diversion, for older patients with multiple medical problems that might not heal in the best way, we think about an ileal conduit. For a healthy fit patient that might be younger, that still lives a very active lifestyle and is not ready for a urostomy bag, we would lean towards a neobladder.

That doesn't mean that you can't have a fifty-year-old that wants a conduit or perhaps a seventy-yearold that really wants a neobladder. This is just the idea is that every case is different and it kind of depends not just on the cancer, but on the overall patient health and wellbeing and then what their preferences are for how they want to live their lifestyle. I will say that I have a lot of patients with urostomies and neobladders that do all kinds of activities. They do yoga, they ride motorcycles, they play golf, they fish. And so keeping in mind the kind of activities you want to do after surgery and sharing that with your surgeon is an important way to help you figure out what the best choice for you is.

# Stephanie Chisolm:

Right? Yeah. You can play pickleball with an ileal conduit.

## Dr. Matthew Mossanen:

Definitely.

# Stephanie Chisolm:

As you can also with a neobladder or an Indiana Pouch. So if that's in your future, that's definitely something to bring up to your doctor.

## Dr. Matthew Mossanen:

I will actually add one thing to that. I did have a patient that was trying to figure out which one they wanted, very fit, and so the patient actually put on a urostomy bag before the surgery and kind of took it for a test drive and did some yoga poses and kind of stretched and just got a feel for it. And I thought that was a very creative way to figure out what life would be like with his stoma.

## Stephanie Chisolm:

Sort of do the Costco model, try it before you buy it. Right? Okay. So you talked about the difference between the length of robotic surgery versus open surgery, but can you give us a best guess? I know each situation is unique, but in general, how many hours are we talking for the surgery?

## Dr. Matthew Mossanen:

Maybe an hour, maybe an hour and a half. Kind of depends on the patient's anatomy, but it's typically okay to think that robotic surgery will take a little bit longer, but the incisions are a little bit smaller. The recovery depends on multiple factors. And so when the patient is ready to go home is usually driven by when they're eating and passing gas and their pain is under control. And so once they have good eating, good bowel function, they're ready to go. So those are kind of the key things we think about.

I don't know, I think it's usually a surgeon is more used to doing one or the other or they do a little bit of both. It's important for the patient to just bring it up with a surgeon if they have any questions about it. But the long-term cancer outcomes are the same.

## Stephanie Chisolm:

So Dr. Mossanen, I remember that you had started cystectomy bootcamp a while ago. Do you still do that and what's involved in that? So bootcamp is more like prior to you going through surgery, you get yourself ready. Do you still do that?

# Dr. Matthew Mossanen:

That's a great question. The short answer is yes. So I really believe that the time before cystectomy is valuable. Patients are either waiting for their surgery or they're getting chemo. And so we have a program at our institution where patients can do an educational class on Zoom with the nurses that will take care of them after surgery. They can also do some zoom exercises with an exercise physiologist. They practice some stretching, strength training, some conditioning, and try to use the four weeks before cystectomy to kind of get a little bit more fit. We also give them some nutrition shakes to help sort of boost up their nutrition 'cause their appetite is not great after a cystectomy. It takes a while to recover normal eating. And of course quit smoking. It's the number one thing.

But yeah, so we do have a pre habilitation program and I know there's a lot of great programs out there at other institutions and things that are being studied that are on the horizon. But yeah, you can always ask your surgeon if there's any programs that they can recommend or refer you to for nutrition, for exercise, for a number of things to help prepare you better.

# Stephanie Chisolm:

I understand that the Indiana Pouch does require a unique perspective. They're creating a little internal pouch, just like a neo-bladder and connecting it with a stoma usually behind the belly button. Do you do those on a regular basis or is that just a few... I hear different stories that not everybody does those.

## Dr. Matthew Mossanen:

I have not done it in years. We don't do it that often. It has to be the right patient. It's not a commonly done operation, but it can be done. We can do it if we needed to. The most common one I do is the ileal conduit, and that's just probably a reflection of the patient population that I see. Bladder cancer patients tend to be in their seventies and have multiple or many medical problems. And so for those patients, typically the first choice is a urostomy. But for any patient in their fifties or sixties young, fit, that really wants to have an active lifestyle and avoid the bag, we'll often go into a lot of detail about a neobladder.

## **Stephanie Chisolm:**

Okay. Well here's a good question. When the bladder is removed, what happens to where it was, the space?

## Dr. Matthew Mossanen:

A lot of people ask that question. That comes up... The intestines just kind of slide down into that space. So the pelvis is filled with the intestine, and kind of slides down. Right now in the normal picture, a normal anatomy, the intestine are sitting on top of the bladder. So when the bladder comes out, the intestine just filled the space.

# Stephanie Chisolm:

And in any of the diversions, they're using a piece of intestine. And does that impact a person's nutritional status because they're missing sometimes a bigger piece than others?

## Dr. Matthew Mossanen:

We try to use a piece that will minimize that. There are some blood tests that we do after surgery to monitor certain vitamin levels. Your surgeon usually checks those and it's possible that you can eat supplementation. But in general, the amount that we remove allows you to be able to extract food nutritiously and be able to eat the regular foods that you were before your cystectomy. But it's because we use a specific part of the intestine.

# Stephanie Chisolm:

Okay, here's a participant who, a woman who had a neobladder one and a half years ago for high recurrence low grade bladder cancer. "My urether was also and replaced with intestine. I developed incontinence overflow, then went to self-cathing. Docs now think I have a stricture in my urethra. I have catheter prep for urethra reconstruction. How common are urethral strictures post-cystectomy."

## Dr. Matthew Mossanen:

Okay. There are a lot of steps to that question. So how common are urethral strictures? So, yes.

# Stephanie Chisolm:

Or she said urethral in there, but it might also been ureteral.

## Dr. Matthew Mossanen:

Maybe it was the ureter... So ureteral. I think it's probably the ureteral, but the ureter, and this is also important, a lot of patients will say ureter and mean urethra or urethra-

## **Stephanie Chisolm:**

Correct.

## Dr. Matthew Mossanen:

We'll just say that it's ureteral. The ureters carry the urine from the kidneys down to the bladder. They're very small tubes. They're about the size of a straw and they can often get scar tissue and need to be reconstructed. That's common. If it's the urethra, which is the tube that goes to the outside world, it's not that common, but it can happen.

## Stephanie Chisolm:

Right. And yes. Okay. So next question, and I think this is a good one. "Is chemotherapy always recommended before having a cystectomy?" That's known as neoadjuvant chemotherapy. What does it do and is that standard practice?

## Dr. Matthew Mossanen:

Where I work, I will not feel comfortable taking a patient for cystectomy until they've seen medical oncology, especially if it's muscle invasive. So for any patient with muscle invasive bladder cancer, they absolutely should see a medical oncologist to discuss neoadjuvant chemotherapy. There are a number of reasons for that. One, it can improve their outcomes. Two, a medical oncologist is extremely qualified to discuss the risks and benefits of neoadjuvant chemotherapy. Three, very few patients are able to get chemotherapy after surgery because it's a long recovery. That being said, for non-muscle invasive tumors, there's no defined rule or standard role for neoadjuvant chemotherapy.

I don't know how to say it, but for patients with non-muscle invasive bladder cancer that has come back after BCG or other chemotherapies, there are a number of trials that are in progress that are looking at alternatives to cystectomy as a way to preserve the bladder. So stay tuned because there's literally been an explosion of trials out there that are looking at alternatives to this exact operation. So it's really exciting and it's still evolving. But that's a great question. See a medical oncologist or ask your urologist if they think it's appropriate for you to have a consultation if there's any question.

# Stephanie Chisolm:

Yeah, here's a good question because I hear about peristomal hernias a lot from patients who especially have had ileal conduits. "Are you aware of any newer or better approaches regarding repairing a peristomal hernia since those recurrences are so common?"

## Dr. Matthew Mossanen:

So we refer our patients to one of usually two general surgeons here that do a lot of those repairs. So just like we said with the cystectomy and those slides where it matters that the hospital does a lot of them and the surgeon does a lot of them, same thing with peristomal hernia repairs. So I tend to send them to some general surgery colleagues that have a lot of experience. They tend to use mesh to repair everything. And the biggest risk factor, one of the biggest risk factors for getting a peristomal hernia is

having a hernia in another part of your body even prior to the cystectomy. So a male patient with an inguinal hernia that gets a urostomy is at a higher risk for getting a hernia near the urostomy.

# Stephanie Chisolm:

Okay, great. Well, here's a question, but I'm not quite sure and I think this is what I'm going to interpret it as. "My most recent high-grade tumor is near the muscle, but no invasion. Prior intravascular treatments were very damaging and my bladder capacity is so small." Would this person, even though they don't have muscle invasion, be a candidate if they were tired of a small bladder for having bladder surgery?

## Dr. Matthew Mossanen:

I think that's a really good question and I'm sorry to that patient for having that problem. That's tough. Thinking about bladder function is an important decision when considering cystectomy. So if you have cancer that's typically not treated with a cystectomy, but you put that cancer in the setting of poor bladder function or not great quality of life because of bladder issues or urinary issues, you might be a good patient, a good candidate for a cystectomy. So I have had some men with really bad urinary problems and then dangerous bladder cancer and after their cystectomy, they actually had a better quality of life because they weren't going to the bathroom that often. So it's unique case by case, but certainly something to consider if you have poor bladder function.

## Stephanie Chisolm:

Right. And so when somebody's going for an ileal conduit, they would meet with the wound and ostomy nurse to determine the best place for putting the stoma, for one thing. They also will be educated about the appliance, the wafers that go around it and how you attach the bag and everything else. So there was a question that was related to leaking on an ileal conduit, but I think that's mostly related to the bag seal. So you would always refer a patient to the wound and ostomy nurse for how you deal with that?

## Dr. Matthew Mossanen:

They all have to see the wound and ostomy nurse before surgery for the marking and then before surgery, I always take a look at it when they're... right before they roll back surgery, I have them kind of sit down and stand up just so I can get a sense of where it is. But leaking, especially in the first couple of weeks is very common because you're learning how to put on the wafer, you're learning how to put on the barrier paste, and there are all these things you're learning. So it can sometimes be a little discouraging to patients, but I try to reassure them that eventually you're going to wake up, you're going to brush your teeth, you're going to fix your bag, you're going to head out the door. So it'll eventually become second nature.

## Stephanie Chisolm:

Great. "For men with muscle invasion of the bladder, how common are removal of both the bladder and prostate?" Is that like a standard procedure, they just take both out so close?

## Dr. Matthew Mossanen:

It is. It is. Yeah, the standard approach is to take out the prostate with the bladder. Is rare, case by case. If someone's really interested in nerve sparing, we can do a nerve sparing cystectomy. And I think that's

probably as much detail as they're asking for. But asking about organ sparing is something that usually depends a lot on the patient's function and their cancer stage.

#### Stephanie Chisolm:

Dr. Mossanen, this has been a delight. I appreciate it. We're looking forward to many more webinars with you. We know we have one that we have to schedule, so we're looking forward to setting those up. Thank you so much for joining us this evening. I appreciate it. And thank you all for coming. Bye-Bye.

