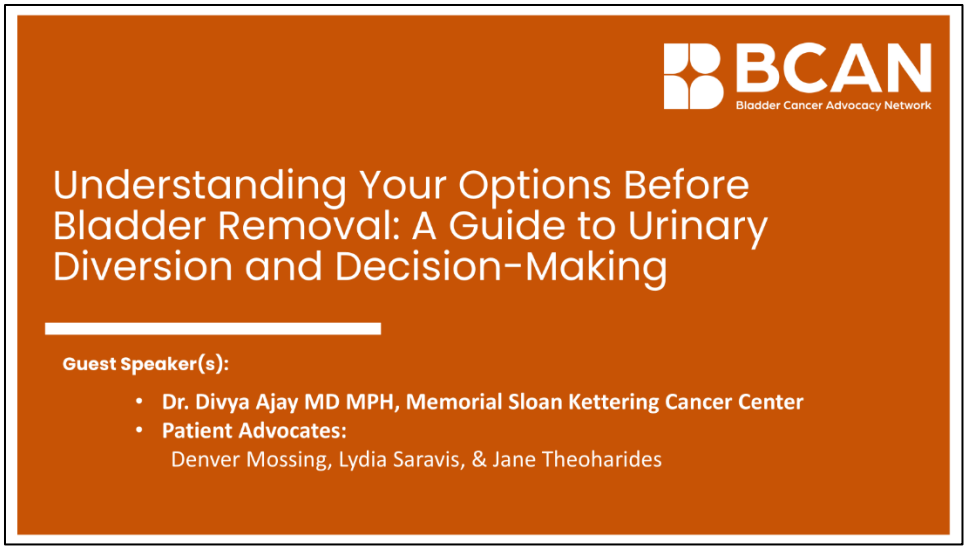

Patricia Rios:

Thank you, Jane. And thank you for sharing your journey with us. Wow. Those were three really impactful stories and really practical tips also. I have a couple more questions for the three of you, but I think what we're going to do, we're going to go into the Q&A session. So I'll save them for a little bit. So I see Dr. Ajay's back on the screen and we have a few questions that were submitted via the chat. If more questions come to mind as we have this conversation to those who are listening, please feel free to enter them.

We also did receive some questions in advance, so I'm going to address those first and then we'll go to the chat as well. So Dr. Ajay, there was a question by one of our participants who wanted to know, how many resections can you do before making a decision a bladder removal is needed?

Dr. Divya Ajay:

It really depends on the grade and the stage of the cancer and what has already been tried and what the patient's response is. So it's not about number of resections. It's sort of what grade and stage the patient is at.

Patricia Rios:

Thank you for emphasizing that. When it comes to diversions, do you find that one may be most commonly used among women or say the gender may benefit more from a certain diversion? What are your thoughts on that, in terms of what you see?

Dr. Divya Ajay:

As you can see from our panelists. I will say there are certain medical criteria that you have to meet to be able to get an internal diversion that includes where the tumor is and that you have decent kidney and liver function to be able to tolerate. Because as you can imagine, the bladder is just a storage reservoir. It just holds urine. It doesn't necessarily interact with urine. Bowel is not made that way. Bowel is made to interact with whatever goes through the bowel.

So bowel will actually take up urine, will actually absorb some urine. So if you're coming in with kidney issues, you're not going to be a great candidate for internal diversions. There is a list of other medical issues as well that we have to review, but it's not a gender related fact. In the decision aid, we do talk about the ... When you're discussing the internal diversions, we talk about the neobladder and how there is a higher risk of what's called hyper-continence or inability to empty your bladder completely. That is higher in women than men, largely because you're using some of your own core strength to empty the bladder because the neobladder does not have an internal muscle like our natural detrusor muscle does have. And also with certain nerve sparing practices.

It is a little bit different in women than men. But outside of that, there isn't a gender preference. It really is the patient's preference and also what medical factors are involved in the decision-making.

Patricia Rios:

Okay, excellent. Thank you for explaining that. What about age? Does age also play a role?

Dr. Divya Ajay:

I mean, age is ultimately just a number. It depends on ... I mean, I've seen 97-year-olds that we've done surgeries on and they've just done amazing and I've seen 50-year-olds who've had multiple cardiac bypasses. You're not a good surgical candidate. So it is ultimately a number, but we do see that patients who are over maybe 75, 80 years of age or so. Their sphincter function, both anal sphincter and the urinary sphincter is a little bit weaker. It just depends on that conversation of making sure the patient's expectations are appropriate.

I know at MSK ... So after 75, they generally don't offer radical prostatectomies for patients who have prostate cancer. And it's the same thought process, is that if you're looking for a neobladder, where the urine is coming out through your natural urethra. If your urinary sphincter is not that great, your chances of leaking and having other issues is going to be higher. That said, again, age is just a number and it really is a one-to-one discussion based on the patient's health and their overall physical fitness and mental fitness.

Patricia Rios:

Okay, thank you. So it's very important to have that conversation and have the assessment with the healthcare team. All right. I have a couple questions for Denver, Lydia, and Jane, and then we'll take the questions that I see in the Q&A chat box. So Denver, Lydia, and Jane, is

there a question you wish you had asked before surgery? Thinking about eight years ago or so, if you can think back, is there something that probably comes to mind?

Lydia Saravis:

I have to say that I asked a lot of questions. I may have been annoying, but I encourage people to ask as many questions as they feel they need to make a confident choice.

Patricia Rios:

Thanks, Lydia. Jane, you also had something to add.

Jane Theoharides:

I asked lots of questions about UTIs and peristomal hernias, but I was not aware of prolapse issues. And I'm not sure if they are more common in females, but I would definitely encourage women at least to ask questions about the possibility of prolapse and if anything can be done to help to prevent that.

Patricia Rios:

Great question. Denver, I think you also had your hand up.

Denver Mossing:

Yeah, I just wish that I had more time from the time of the true diagnosis after the last TURBT to when the surgery was, because I didn't have any chance to do much research. So a tool like this would've been very helpful to be given out, not having a lot of time, but I wasn't even aware of BCAN at the time of my surgery. So all of this came after and all my knowledge came after. I wish I had known more and knew more what questions to ask. When you're hit with the big C, you don't even know what to ask because that's all you're thinking about is, "I have cancer, I have cancer and this is going to take care of it, removing it. Okay, great." You're so overwhelmed with what's going on, timing and any resources can help.

Patricia Rios:

Thank you, Denver. That's why I think I like Lydia's advice, if you can take somebody with you to those appointments, we encourage you to do that. There are resources available to help you and I know we have plenty at BCAN. Those of you on the screen are a great resource with the support groups you lead and also volunteers for S2S. I keep saying this, I'm going to go to the question in the chat, but Dr. Ajay, I just wanted to ask if you could explain prolapse and address that, if there's any concerns or things that patients should consider.

Dr. Divya Ajay:

Sure. Prolapse is rare. We have studied this and it is more common, of course, in patients who don't have organ sparing. So if you have organ sparing surgery, the uterus is held up by its own reference points. So the prolapse is rarer in patients who have spared their organs. So I would say it's very challenging.

There's also two different types of prolapse. There's one type of ... We call it prolapse, but it's not really prolapse. It's where the vagina is shortened. We take the vagina and we sew it to the tissues around the urethra, once the urethra is resected and that anastomosis essentially separates. So what you are seeing prolapsed is not really vaginal tissue. Vaginal tissue is actually very strong and firm and healthy. It has three layers to it and it can be repaired.

But this tissue that is the separation of the vagina to the periurethral tissue is more like a dehiscence and that's what we see most commonly in post-cystectomy patients. It can be fairly mild, where there's just a bulge and that dehiscence causes leakage, which is very bothersome because you have to start wearing a liner, or it can be very severe. In some very rare cases, we have actually seen more severe outcomes in that situation. Again, prolapse is not ...

It is very rare. I would say maybe 6 to 10 a year among hundreds and hundreds of patients, and it's also very difficult to fix. That said, there is more awareness of it. There's more publications. So there are things that are being done intraoperatively. I'll say one of my colleagues at MD Anderson is really propagating doing more organ sparing. The uterus doesn't always need to be taken. So that's another important conversation. Does the uterus have to be taken as part of the surgery? Maybe it doesn't.

So that's one preventative thing. There are also surgical techniques that you can do to support both the anastomosis, where the vagina and periurethral tissue is attached together. And also, if you come in with prolapse, things that can be done to buttress that area.

Patricia Rios:

Okay. Thank you. And Dr. Ajay, do you have any tips for patients to bring up that conversation around organ sparing, when they are having a conversation about the surgeries?

Dr. Divya Ajay:

Yeah, absolutely. This is mostly in women. So in organ sparing with respect to women. Not doing a prostatectomy in men is fairly rare nowadays because there's a risk obviously of prostate cancer, which is another conversation. But coming back to the women conversation about organ sparing. It used to be the default, where we always felt like the urethra was part of the anterior vagina and the uterus was close enough to the bladder and why was it necessary? But now there's more and more data that the uterus does not actually need to be taken.

The main source of issues like ovarian cancer are the fallopian tubes. And as long as you take the fallopian tubes, you don't have to take the ovaries, you don't have to take the uterus. I think having that conversation, what exactly is going to be done as part of the surgery and what needs to be done? Now we have all this great imaging with MRIs, that'll actually tell you, is there an invasion? Is there any adjacent organ concerns? Most of the time you can get away with organ sparing and not have any problems.

Patricia Rios:

That's definitely comforting to hear. One of our listeners today wants to know, how do you stop burning in the urethra?

Dr. Divya Ajay:

Yeah, this is tricky one because I don't know if he's had a cystectomy, or this is after a TURBT, after just the first resection, as everybody here knows that causes a lot of burning for multiple reasons. Number one, there was just a scope in the urethra. Number two, the inside lining of your bladder is like the inside lining of your mouth. It's soft and mucosa. When we resect that, it's replaced by scar tissue. So that replacement itself and that process of healing causes a lot of burning. A lot of times we associate burning in the urethra with urinary tract infections in rare cases, with sexually transmitted diseases or vaginitis. This is a man, I'm sorry. So that's not an issue.

Other things are pelvic floor issues. Somebody had brought up going and seeing a pelvic floor physical therapist. That is a great option. In patients who are post-radiation, I don't know if he's had any radiation. You do a course of NSAIDs or anti-inflammatories, a course of steroids can sometimes help. Vaginal or rectal Valium can sometimes help, but I would start with understanding a little bit more about, when did the burning start, what caused it? And then other factors around his urination.

Patricia Rios:

Excellent. Thank you. It's a broad question, but you did a great job helping us think through that and the conversations that we should be having with our providers. So the next question is from another listener who is saying that they had urinary retention for four years and their doctor does not know what's causing it and has been using intermittent catheters to empty the bladder three times. Considering this information, is neobladder still an option? Are there other things that this individual should consider? Specifically they're considering neobladder.

Dr. Divya Ajay:

Sure. Yeah. Again, there's a lot of things that need to be discussed from a one-to-one basis here, to understand the details of the case. When you think of somebody not emptying the bladder, think of a car trying to leave the driveway. Is it that the driveway is really clogged with a lot of stuff and the car can't get out? Or is it that the engine of the car is not functioning? If it is an issue with the driveway, I would be careful with a neobladder because a neobladder is giving you a new space to hold urine, but that driveway still needs to be completely functional and normal in order for you to get the urine out.

If it's a problem with the engine, then essentially we're replacing that engine. So there should not be an issue with it. Again, the cautionary advice with the neobladder, you're taking home this brand new organ. You have to train it. You have to learn how to pee, which is a whole different way of urinating than how you urinate beforehand. So you have to be prepared to do the work to train that organ.

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