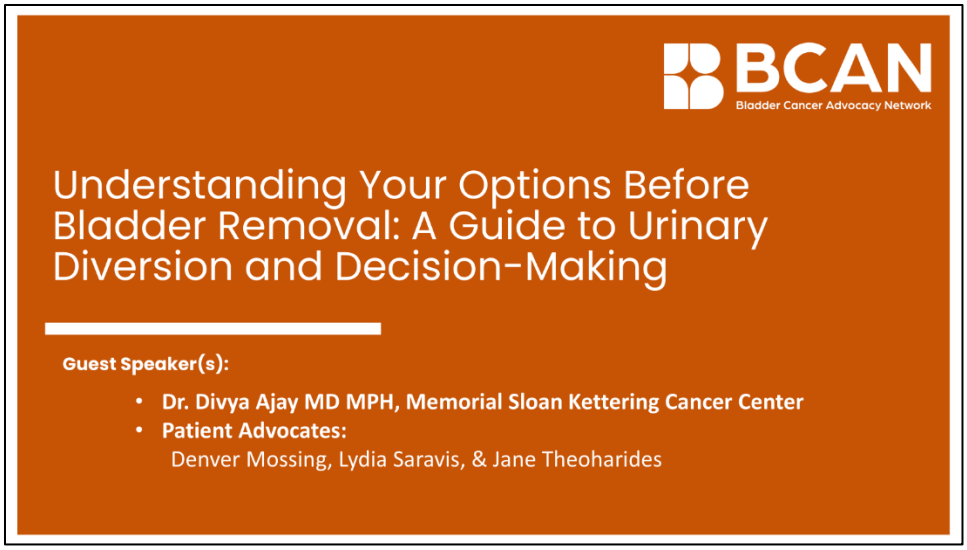

Patricia Rios:

Thank you. There's a question about recovery time and I would love to hear from Dr. Ajay what you see in clinic in terms of recovery for patients over time. But I also would like to hear from our patient advocates in terms of how long it took you to … What that recovery window looked like. So we'll start perhaps with you, Dr. Ajay, and then we'll hear Denver, Lydia, and Jane in that order.

Dr. Divya Ajay:

Sure. Yeah. We asked patients when we were interviewing them and what we got was about six weeks to about three months for the ileal conduit. And with the neobladder, again, the recovery for the patient really depended on how much time it took them to train the internal reservoir. So that was anywhere between six weeks to six months or so.

Patricia Rios:

And Denver, what was your experience like?

Denver Mossing:

Yeah. With the Indiana pouch, my surgery was a little more extensive because I did have to have the urethra removed. So my recovery time actually wasn't as bad. I probably was at home and out of work for three months. And after that time, I did go back to work and I was retaining for three to four hours at that point. So I was doing really well.

Patricia Rios:

Thank you, Denver. Lydia.

Lydia Saravis:

Yeah, thanks. If I could want to specify a little bit of what that training means. It's a process where you're … After the surgery and after my Foley catheter was removed, I had zero control. So I was wearing a pad, but I was given instructions to do exercises and little by little over time I was able to hold for a little bit longer before having to go to the bathroom. And what that process means is that as I was able to retain more urine for longer periods of time, the bladder could stretch a little bit. So it was sort of like a yin-yang.

As you held a little bit longer and the bladder stretched a little bit, you were able to go longer between bathroom visits. And that process does vary widely between people and I agree with Dr. Ajay's timeline. For me, my daytime continence came by six weeks and my nighttime by four months, but I was very vigilant about my exercises. I think that made a big difference. The bigger challenge for me in my recovery, which took much longer was fatigue. And that was just a function of adjusting after the surgery and just how it impacted me personally.

Oftentimes people are told it's a year and in my case it was, in terms of getting my full stamina back, but my continence came I think in a reasonable amount of time. As far as going back to work, I do have some people in my group who went back to work part-time at two months, but seems more the regular experience, the typical experience is people go back to work after three months.

Patricia Rios:

Thanks, Lydia and Jane.

Jane Theoharides:

I would say it was probably about three months for me because it was the winter and it was also COVID. So it wasn't like you could go out to a coffee shop. We didn't go anywhere. We were super careful. So I would say probably three months. And I think the biggest thing for me is to realize that recovery is not linear. I mean, in the hospital I was just sailing along and everything was wonderful. I mean, I was told by several doctors, I was the most aggressive post-op person as far as walking and everything. But then I came home and there were like little blips.

There were days that I would be down and I would be really fatigued and depression was very real for me. So just remember that recovery is not linear. Just because you're going right along full forced and everything looks great that it's not going to … Maybe for you it'll stay that way, but for me it didn't.

Patricia Rios:

Thank you, Jane. We have a few more questions, so I appreciate everyone staying a little extra here with us. Dr. Ajay, can you speak a little bit about other treatments that are used to treat the bladder? For example, you mentioned radiation, there's a question here about radiation as well. What role does it play in treatment for bladder cancer?

Dr. Divya Ajay:

Yeah, absolutely. At their latest ASCO meeting, there's a lot of interest now in bladder preservation options. So radiation and also just observation. So you can do EV-Pembro or one of the new treatment options and then just wait to see how things go. I think there's a lot of data that's still pending and we are asking these questions and we are investigating and it's a really interesting space.

The radiation in particular, I'm ... I think we need to just proceed with caution. I think there's a lot of enthusiasm to preserve people's bladders. However, sometimes, like I told you, the bladder. We don't think about it until it starts giving us problems. The bladder does play an important role. It has a very unique property that almost no other organ in the body has, which is compliance, which is this ability to hold and hold and hold without pushing urine up towards the kidney or pushing urine down to the urethra. And once you resect some of that mucosa or the tumor within the bladder, patients can lose compliance. BCG and other treatments further lose compliance.

So in patients who have urinary leakage or any concern for upper tract damage, radiating their bladder is really not a good option at all. It's something we need to move with great caution. One of my roles as a reconstructive urologist nowadays has been to perform what's called urodynamics testing and other testing for patients who are going to be preserving their bladder, to make sure the bladder is healthy enough to actually preserve because not only are we dealing with cancer, we are also dealing with function.

So while it is very exciting and cancer-free survival and stuff like that is promising, I think people just need to think very carefully about the function of the bladder as well.

Patricia Rios:

Thank you. And thank you for addressing the bladder preservation as a emerging sort of theme in the space. There is a question about the role that ... In this case, neobladder and its role in sexual intercourse, Dr. Ajay, I don't know if you have some information to share and then I also welcome our patient advocates, anything to add that has been identified as a priority by our patients. Also, how do they have the conversation with their surgeon as they're also having conversations about the diversion and the importance this is for them?

Dr. Divya Ajay:

Yeah, this is a very important conversation and we have asked patients over and over again and they feel like they were not adequately maybe counseled on this. More women than men, but this is definitely something that needs to be addressed. In men, it is all about what kind of erectile function you come in with and how much of the nerve sparing technique can be performed based on the cancer. Like Denver was saying, if you have cancer in the prostate as well and the prostate needs to be taken with wide margins, then the nerves going towards the penis are not going to be able to be spared as well in which your natural erections are not going to be that great.

That said, there are medications like Viagra, Cialis, Levitra. There's injection therapy that men can give themselves. And then of course, there are penile prosthesis. Like a breast implant, you can actually get an implant inside the penis that you can give yourself an erection.

In women, while the nerve sparing is important, a lot of it for intimate intercourse is length of the vagina. And that goes back to what I was saying with organ sparing techniques. When the vagina and the uterus ... The vagina length is essentially spared, you could just go back to having intercourse just like you were. My colleague, Bernie Bochner, who's one of our big cystectomist here, did a study on quality of life in patients with urinary diversions. We found the patients with ... Female patients with neobladders had the fastest recovery, as far as sexual health was concerned among the different groups because they by far had more vaginal length and more sparing of the organs.

That said, even if you have a short vagina, you can start using dilators and you can start using vaginal estrogen and other techniques to help the vagina be able to have intercourse. The clitoris is generally spared if there's a nerve sparing technique, but that is again, a conversation to have. Like, "Can I have a nerve sparing technique? Where is my cancer? How is this resection going to be done?" Those are things we need to ask upfront.

Patricia Rios:

Those are excellent points. And because it's so important, that will be a topic at our Patient Summit in August. If you are not able to join us, we will be recording. So thank you. One last question before we do closing thoughts. And the last question ... I mean, I think Lydia kinda touched on this, but Dr. Ajay, I would love to hear your thoughts on, how do patients evaluate if a surgeon is skilled enough to deliver optimal results and what does that mean for the specific diversion? What tips would you give patients as they are looking to see who and where? So any thoughts you can share with us would be super valuable.

Dr. Divya Ajay:

Yeah, this is a very tricky thing in healthcare. My son is getting ear tubes and I don't know how to evaluate who is good and who does how many and how good they are at that. So I think I agree with everything has been said so far, is go to the Survivor 2 Survivor, ask other people who they used. Look at BCAN's website, look at the big urology conferences, who are the big academic urologists? In general, I will say if you're having an internal diversion that is in general more commonly done in big academic centers. And if you're going to a private practice or ... that's generally, they can be extremely skilled, but the internal diversions require a bigger team and that sort of big team is generally more available in big cities, big academic centers.

So take that and then think about, who are the people who are speaking at conferences about these things? Who are the people who are writing papers and publishing in this area and who are the people who are getting good feedback from other patients? As far as what their skill level is and what the individual patient outcomes are, that's actually very hard to find. That information is hard to find.

Patricia Rios:

But those are very practical tips, so we greatly appreciate that, Dr. Ajay. We are way over time, so I am grateful to all of you and our listeners for staying with us for this much needed conversation. What I would like to do is I would like to ask our panelists today to share some closing thoughts. And so what would be the takeaway that you would like patients to remember as they listen to this webinar? And what we can do is start with ... Let's see, Denver, Lydia, Jane, and we'll close with you, Dr. Ajay, if that's okay.

Denver Mossing:

I think that all of us would say that our diversion is wonderful. We're glad we have it and we are alive and kicking. I tell people all the time, the Indiana pouch is the best thing there is and I'm sure that everybody says that about their diversion. That being said, the importance of having a great doctor, which I did and knowing what they're doing is huge and I'm so glad I found Dr. Pohar when I did. But life goes on and life is very good. No limitations whatsoever in what I do and it's wonderful.

And I would recommend if you're going to make the decision, make the one that's right for you, what feels best. This tool that they've come up with is wonderful and thank you to BCAN for being there for everybody. And Patricia and Allison, thank you for everything you guys have done.

Patricia Rios:

Thank you, Denver. Lydia.

Lydia Saravis:

Wow. So much covered today. I want to thank Dr. Ajay for covering everything so adeptly and for Denver and Jane as well. I feel like I dodged a bullet. I feel like the luckiest person. Yes, I had bladder cancer, but yes, I had access to this amazing surgery and I had a really good outcome. Life goes on. Life is good. I'm not limited in any way. It is a very tricky decision to make. I know I struggled myself quite a bit.

I tell people who are trying to figure this out, ask your surgeon, "How many of these surgeries have you done? How do your patients do, especially for women?" The feedback I've gotten is that most doctors are pretty honest with their answers. I just say ask questions. Don't hesitate to get the answers you need, so that you're comfortable with your choice, but there is good life after diversion surgery, definitely.

Patricia Rios:

Thank you, Lydia. And Jane, your mics on mute, but we're ready for you.

Jane Theoharides:

I'd say talk to as many people as you can that have the different diversions. Do your research and really figure out what matters to you because you're the one that's going to live with it.

Talk to your spouse. And I think the document that Dr. Ajay developed is wonderful. Sandy sent it to me and I read it. I've read it three or four times. I've passed it on to a bunch of people and even being six years, just about six years out, it was valuable to me to read it. It reinforced the decision that I made. That I made the best decision for me. And thank you everyone for today. It was great.

Dr. Divya Ajay:

Yeah. Thank you so much again, Patricia and Allison. It was so nice to meet Denver, see Lydia again and meet Jane and Zoe. It's nice to interact with all of you and hear live that you're doing so well and thriving. We see patients less frequently as they go out and we see patients more frequently immediately after surgery. And sometimes when people are struggling, it's nice to know that a few years down the line they're going to be thriving as you are.

The next step with our project, which I'm so excited about is to take this and make it into an interactive AI tool, where essentially you can interact with this information slightly differently because the feedback we're getting is people are really not into downloading and reading bunches of paper and they want little TikTok videos or little short pieces of information. I'm really excited about that project, where ... Dr. Bochner is really involved with that and we're trying to develop these AI avatars that can talk to you and provide you with good information because there's a lot of bad information out there too.

So stick with BCAN, stick with these good places that give you proper information. And we need to keep collecting data. We need to keep thinking about outcomes. We need to keep asking the difficult questions. And I like that all of you are so involved and interested in doing that and I would love to keep doing that with you.

Patricia Rios:

That was wonderful. Thank you, Dr. Ajay. Thank you, Denver, Jane, Lydia for joining us today. Dr. Ajay, a huge thanks to you and to the team for developing such a very useful tool. I know that will be the gift that keeps on giving, so we will be making sure that every patient that contacts us, especially with our S2S program, gets a copy and is able to use that to help them with their decision. And to those of you who are listening today, we hope you found the webinar useful, know that we are here to support you and there's resources. We're looking forward to what's to come, 2.0 of the tool and how we can continue to use that.

SPONSOR