

## **Question and Answer:**

**BCAN-Stephanie Chisolm:** Do you have any advice on what to do if the scrotum and penis remain somewhat swollen from lymphedema?

**Dr. Matthew:** Yeah, so just a reminder, and it's important that I am a psychologist. So it's more challenging for me to answer the medical questions. And so I'll answer them not necessarily from a from a physician's perspective, but from experience perspective is that that can be very uncomfortable, obviously. And usually the edema goes down over time. So I'm not clear how long this has been going on. But it is definitely worthwhile to talk to your oncologist or your urologist to find out further about this edema and the expectation that it will go down, and the idea of being patient because it is uncomfortable. So reduce your expectations that you're going to engage in sexual activity, merely because of the discomfort and hopefully that will improve. Go back to your healthcare provider, because they would be the ones that would be able to provide other sources of relief in that sense.

**BCAN-Stephanie Chisolm:** If somebody who can't take Viagra or other meds because of hypertrophic cardiomyopathy, other than injections, are there any other interesting safe methods on the horizon that you would know about?

**Dr. Matthew:** Yeah, not that I know of, unfortunately. You know the latest as you know, big change were the PDE5 inhibitors and I'm sorry to hear that that's not available. Hopefully, you've talked to your cardiologist specifically about it, because they actually know more about it than for instance, urologist. So it's worthwhile to go back, but certainly be saved. The benefit of Muse, that's that micro-suppository or the injections is they're localized agents. So they only work in the penile tissue, and hence, they're not problematic under the situations of cardiovascular morbidity. And so that's why you're probably available to do it. So a couple things. One is, when you're thinking about injections, if you've not tried them, as they said, the bark is far worse than the bite. And it doesn't also mean that you have to use it every time. And I think that's super important too, because no one wants to think that every time that they're going to engage in sexual activity, they're going to use an injection.

But lots of couples will say, "It's nice just to have it there, once a month or once in a while just to get back from erection." So if you haven't tried it, talk to your healthcare group. And see if you can even go

and get training in a clinic on how to do it and how to do it successfully. The other idea is Muse, that's that micro-suppository. Yes, it's less successful, but that doesn't mean it's not successful. And the idea if used properly, in other words, if you put it in and you massage your penis, with your penis pointing up towards the sky, and there's full absorption, it can also be helpful. And then finally, the pump. And the pump probably has a bad rap from Austin Powers, when he pulls it out of his box as a item and when he was in prison or something. But the idea is that they also can be helpful and useful, and there's not ... and you get better at.

If you're trying to pump and putting the ring on, and it's uncomfortable at first or whatever, you can learn different ring sizes, there are videos on YouTube that can help. So those would be my recommendations. But unfortunately, I'm not aware of anything like a top cream or anything along those lines that will be effective enough, given the degree of erectile dysfunction associated with this treat.

**BCAN-Stephanie Chisolm:** And you mentioned one thing when you were talking about the injection you were talking about it's like a vaccine. And I know that it really is a very tiny, very fine needle, I think that's important to stress. Because a lot of people are seeing the videos of people getting their COVID-19 vaccine, and I personally think that's a really big needle. **And so it's not like the vaccine needle at all, really, in most vaccines. It's a very tiny, almost like a, isn't it more like a diabetic needle?** 

Dr. Matthew: That's right. A very small needle. A very small gauge.

BCAN-Stephanie Chisolm: Yeah. Okay. Are they unique?

**Dr. Matthew:** I was just going to say the overwhelming sensitive area of the penis is the head of the penis, not the shaft of the penis. And of course, you never would inject in the head of the penis, you inject near the lower bottom portion of the shaft of the pianos. And as I said, people immediately step back a little bit, but those that have tried it do state that its bark was worse than its bite, it's just not that challenging to do. And they feel confident because it is a very effective approach.

BCAN-Stephanie Chisolm: Or that works relatively quickly to not that you have to wait a long period of time for it to take effect either, correct?

**Dr. Matthew:** Absolutely. And the idea is that, as I said, it takes no more than 15 minutes. And what can actually occur is that you can have ... there are varying forms of it. So you can have it in a powder form. And then you mix it with fluid to make the medication at the time of need. And so you can travel with it. Other times it's already in liquid form and doesn't need to be refrigerated. But the idea is that you engage in sexual, if you engage in some foreplay and you decide that you want to move towards penetrative sex, it takes a very short period of time to load the needle. You're taught how to do so, you're taught how to dose respond, and then you inject yourself. Then you can roll back over in bed or on top of the kitchen sink or wherever you happen to be, and engage in that foreplay again. And during that time you'll, or erection will foam.

**BCAN-Stephanie Chisolm:** So, to jump to one more question, because we are coming towards the end of the hour. So I know that sooner is better, but is there a point after which treatment is no longer effective, for sexual dysfunction post bladder cancer treatment?

**Dr. Matthew:** It was use it or lose it to engage in early pro-erectile therapy, in order to ... for greater likelihood of return to function later on. And try as we might, and although that sounds like a great approach, the research hasn't really bore that at out. All right, it doesn't mean that it's not a very good idea to engage in sexual activity sooner rather than later. Because you don't want a disruption to go on for so long. And the other is that it's nice, it's probably good to get blood flow to the penis to get oxygen and nutrients to the penile tissue. And that keeps it healthy. That said, this early use of say, PDE5 inhibitors have been tested. The idea is that if we do that, then we'll have better natural function a year or two away. And unfortunately, the research hasn't bore that out. That said, we do know these PDE5 inhibitors and pro-erectile agents are useful. So doing nothing, you're going to have less of a chance of getting erectile function.

So going back to the idea of, is there past a time when you shouldn't try it? I would suggest not except for the idea that if you haven't had an erection for a very long period of time, the health of your tissue may be compromised. But that said, I don't want to assume that, and I think you should go see your urologist and give it a try. There's no harm in giving it a try. So don't be, feel fearful that I didn't try it earlier and I should have not blown it. It's just not true.

**BCAN-Stephanie Chisolm:** Okay, that's good advice. Thank you. Another good question. **Since** neither urine nor ejaculate travels to the penis, after a urinary diversion is in place, after cystoprostatectomy, will the urethra close up to where suppositories can't be used, since it's not being used for anything else?

**Dr. Matthew:** That's a good question. And I have to tell you, I've not experienced enough in the use of views under those circumstances to know that because my clinic runs for the first two years, for within two years of treatments. So there's still the likelihood of the closing of the urethra during that time is less. So I know that the Muse applications or the applications of micro-suppositories are thin. But I also wouldn't want you to do any damage. So if you feel like the urethra is closed, and not allowing for the applicator, then definitely just talk to your urologist to confirm and make sure that you don't do any damage if you're going to try Muse.

## BCAN would like to thank our Patient Insight Webinar sponsors



