



Understanding Women's Sexuality after Bladder Cancer webinar

Tuesday, December 1, 2015

Part VI: Question and Answer Session

Questions answered by



Dr. Daniela Wittmann is Clinical Assistant Professor of Urology at the University of Michigan. She is a certified sex therapist and a leading member of the Jan and Dave Brandon Prostate Cancer Survivorship Program at the University of Michigan. She graduated from the University of Keele in the United Kingdom with a degree in psychology and Russian studies and earned her Master of Social Work from Simmons College School of Social Work in Boston. She received her doctoral degree in Social Work from Michigan State University. Dr. Wittman's clinical work and research focus on couples' sexual recovery after pelvic cancer treatment.



LaShon Day received her Masters of Science as a Physician's Assistant at the Wayne State University School of Medicine in 2008. She has been a practicing PA-C (certified physician's assistant) for almost eight years. Specializing in urology in Ann Arbor, Michigan, Day currently works at the University of Michigan Health System's Pre-Operative Clinic.

Moderator: How do you find a certified sex therapist in my community? Do I look them up in a phone book? How do I know who's good and who's not?

Dr. Wittmann: It's a little bit hard to evaluate who's good and who's not with any professional provider. But the American Association of Sexuality Educators, Counselors and Therapists requires quite a rigorous training for sex therapy so many of these people are already very experienced therapists per say. Then they get additional rigorous training which is both

*The **Understanding Sexuality and Intimacy after Bladder Cancer** webinars are made possible by a grant from Endo International plc.*



academic and clinical. And the American Association of Sexuality Educators, Counselors and Therapists' website is www.aasect.org and if you go there, there's a map of the United States. When you click on your state, it will tell you all the certified sex therapists in your state, and then you can find one closer to you. Mostly, sex therapy is done best in the office obviously—you want to be in the office, but some providers will do an initial consultation on Skype and you may be able to get some information just from a consultation, but you may just be able to find a therapist near you—and that's the website to go to.

Moderator: Somebody has a yellow discharge 5 years after having a radical cystectomy with an Indiana pouch. How do they counteract that if they've got this discharge if you've got any suggestions?

LaShon Day: Many times, in a normal vaginal environment we have discharge from time to time, but I would definitely have them address that with their provider, just to ensure that there isn't anything infectious going on. There can be other things that can happen in that environment, you know bacterial vaginosis and other different things that are entirely treatable. I think the real question is though—is it something coming down from there that shouldn't be there—that's probably what this person is referencing. And many times it is normal to have a bit of discharge after having all of this, but I would still have them talk with their provider and also assess if there's blood or anything else that's there that's concerning.

Moderator: Another biology question, "Does anyone know how long menopausal symptoms will last? I was menopausal for 6-7 years before bladder removal and it's been 6 years since then. Now: a total of 13 years with hot flashes, mood swings, etcetera."

LaShon: That's unfortunate, I feel bad for that patient! I'm a little surprised to hear that it's lasted that long, but certainly everyone is a bit individualized with their ability to experience some of those symptoms.

Dr. Wittmann: Menopause lasts very individually for some people, it's kind of a blip, and for some people it's a horrifying experience over a long period of time. So anybody who's got these kind of strong, strong symptoms should be talking to their medical provider or their gynecologist or primary care physician about this because there are ways to try to control symptoms. Sometimes you can have to be on a low dose of an antidepressant, and there may be other ways, but this has really become a medical issue and should be addressed directly. A person should not feel like they have to endure it and live with it.

Moderator: How long does it typically take to lengthen the vagina and how often do you need to use the dilator to accomplish this. We did speak about using a dilator to help stretch and

lengthen the tissues. What's the usual length of time before penetration could be comfortable or better than it was?

LaShon: I think that's also kind of individualized per patient. I think it depends on where we're starting. Is it tough? Is it atrophied? Is it very narrow? And how much, in a step-wise fashion, is the patient even able to dilate? If it's a slow process in moving toward that direction, then obviously it could be longer. We wouldn't want that process to be intensely painful or anything—it should be more in the comfortable range. So I think it's kind of patient-specific and where we're starting and what our end goal is. I mean we all want things to happen “now”, but I think the prescription here is to ensure time.

Dr. Wittmann: I agree with LaShon in that you have to figure out where you're starting, and the thing to do is, go to your gynecologist and find out two things: 1) to find out, for sure, how shortened the vagina is, and then 2) how fragile the vaginal walls are. That will determine where you start. Dilators start very, very narrow and easy to insert in the beginning, and then you gradually go to wider and wider dilator. It can take quite a few months. The person, the professional that helps with that best, is a physical therapist who has expertise in this area of working with them, and a lot of them are. Physical therapists are fantastic resources for people who had pelvic surgery or pelvic radiation or even chemo therapy, because what they will understand is not only what needs stretching but also whether there is any scarring tissue that needs massaging, whether there are any adhesions that need help—they can be extremely helpful but it can take a few months at least. It's one of those situations where it's important to continue to be sexually active without penetration to create blood flow and to have regular sexual arousal and not be as focused on the “when” it's going to happen as the process of getting there.

Moderator: About half of the participants in this program said they have had a radical cystectomy when we asked in our poll—this question is from a patient who asked if she has to have her bladder removed, what can she say to her doctor to encourage them to keep as much of the vagina intact as possible. I know that you mentioned why they would take out the organs that are nearby and what they typically do during radical cystectomy for women, but how can she convey this to her physician?

LaShon: When we see a consult with patients, and we're talking about surgery, I would just make sure that they're aware, that the patient makes their surgeon in the team aware that this is a priority and that this is something that they really want to happen because it's an important part of their relationship. Just have open, frank discussion and hopefully there's a good rapport back and forth that can be established, and that importance is established. Initially, in the postoperative period I don't like for people's expectations to be very high. It's going to take some time to recover from surgery and there are a lot of aspects of recovery that we need to

*The **Understanding Sexuality and Intimacy after Bladder Cancer** webinars are made possible by a grant from Endo International plc.*



focus on, aside from just their ability to have sex and retain intimacy afterwards. We're also treating their cancer, which is important as well, we want to treat the *whole* patient and everything that they're about—that includes their cancer and also their quality of life. Aspects of nutrition and a lot of the other things we focused on are really important during recovery. But it's an open, frank discussion with their surgeon letting them know about the importance of these aspects to their life and quality of life that's probably the starting point of that conversation.

Dr. Wittmann: When you're discussing having a cystectomy, here are the important body parts to sexual function. Ovaries protect/preserve hormones in pre-menopausal women and so there's a question of whether the ovaries can be preserved—sometimes they can, but depending on the disease they cannot be, but that is a good question to ask. They can also preserve the cervix, which is also important to sexual pleasure. Will the clitoris be preserved? So those are the structures that are very much important to sexual pleasure, and certainly as LaShon was saying, for a shortened vagina, is that necessary or not? And they did some research here at the University of Michigan to find out that cystectomy patients tended to focus on sex months after surgery because first they had to deal with recovering from surgery, coming to terms with the cancer like LaShon was saying and so on. So don't rush yourself in any way; you can address it a little bit later on, but if your surgeon knows from the beginning that this is an area of your life that is important to you and that you want as much of your functionality protected they will take care to do it if they possibly can—obviously the cancer is going to be their first priority as it will be yours, but they will be sensitive and thoughtful about it and they'd be willing to address it with you when you're ready to do it after your treatment.

Moderator: I'm sure that an individual would speak specifically to a physical therapist or their sex therapist that they might go to if they were seeking this particular type of remedy—how often should they be looking to use that dilator? Is it something they would do on a daily basis, once a week? What is the typical recommendation for people who are eager to sort of get back that aspect of their lives?

Dr. Wittmann: Probably at least 3 times a week. It's an ongoing thing, and it has to be consistent because the tissues begin to shrink out of you don't stretch them.