Sexuality and Cancer:

Changes, Challenges, and New Approaches

National Webinar Transcript

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Presented by:

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Melissa Rosen: Thank you for joining us today. I want to just start by saying, this is such an important conversation, sexuality and cancer. And it's not always an easy conversation but again, an important one. I also just want to set the tone by clarifying at the beginning that this program is an inclusive one. For those who are partnered, for those who are not, no matter how one identifies, sexuality is an important topic for all. Before we begin, I want to introduce myself and share a few housekeeping details. My name is Melissa Rosen, I will be your moderator today. I'm the Director of Training and Education at Sharsheret. I want to thank our sponsors for today's webinar. The sponsors enable us to continue offering meaningful programs to you, Maze Sexual & Reproductive Health and Merck. And I want to thank our program partners for today, Living Beyond Breast Cancer and NYBRA Plastic Surgery for collaborating with us to enhance support to all those impacted by breast or ovarian cancer.

This webinar is being recorded and will be posted on Sharsheret's website along with a transcript for you to use as an ongoing resource. I want to assure you that participants' faces and names will not be on the recording. And if you would like, you also have the option to be anonymous during today's live webinar. You can turn off your camera and even change the name in your Zoom box. There are instructions on how to do that in the chat box now if you'd like to. I do want to say we received so, so many important questions through registration and I am sure questions will arise during today's presentation. So please use the chat box and we will address your questions during the question and answer period at the end of the webinar. If you'd like your question to be anonymous, you can send it to Sharsheret directly in the chat box.

As a reminder, Sharsheret has been providing telehealth services to the breast and ovarian cancer communities for 20 years because cancer is so much more than simply a physical experience. Sharsheret understands that treatment and survivorship are different for everyone, that's why our Thriving Again Survivorship Kit, which is available to you at any part of your cancer experience is customizable based on each person's distinct needs and interests. Today's webinar speaker, who you see on the screen with me now, Dr. Bat Sheva Marcus and today's webinar sponsor, Maze Reproductive & Sexual Health have partnered with Sharsheret. Not only on the webinar, but also to update one of the add-ons you can select to personalize your survivorship kit about sexual health, intimacy and relationships. We are so proud of this new piece and hope you find it helpful. You can order your free survivorship kit through our website at the link that's being put in the chat now. But if you've already received a survivorship kit and would like to request the newly updated sexual health resources, no problem. Please email my colleague, Aimee Sax and her email is about to go into the chat box.

If you're interested in finding out more about Sharsheret's free confidential and personalized services, please email us or visit our website at sharsheret.org. As we move into the webinar itself, I want to remind you that Sharsheret is a national non-for-profit cancer support and education organization and does not provide any medical advice or perform any medical procedures. The information provided by Sharsheret today and our speaker today is not a substitute for medical advice or treatment for a specific medical condition. You should not use this information to diagnose or treat a health problem, but always seek the advice of your physician or qualified healthcare provider with any questions you may have.

We are so fortunate to have our speaker with us today. Dr. Bat Sheva Marcus is a certified sex therapist and the clinical director of Maze Reproductive & Sexual Health, the largest independent sexual health center in the country. And she literally wrote the book about today's topic. She's the author of Sex Points: Reclaim Your Sex Life with the Revolutionary Multi-point System. And later on in today's program we'll actually give you the chance to win a copy of that book. Dr. Marcus earned her PhD in human sexuality and a master's in public health at the Institute for the Advanced Study of Human Sexuality. She holds a master's degree in social work from Columbia University and a master's degree in Jewish Studies from the Jewish Theological Seminary. She has lectured internationally on women's

issues, gives frequent grand rounds to medical health providers and has been a guest on numerous radio and television shows, including CNBC, CBS News, Huffington Post Live, and most recently NPR's All Things Considered. Dr. Marcus, welcome, welcome. Thank you so much for being here. You are muted.

Dr. Bat Sheva Marcus: All right, there we go. Melissa, thank you so much for having me. You just feel totally free to call me Bat Sheva.

Melissa Rosen: Okay.

Dr. Bat Sheva Marcus: I'm getting little notices, my internet is a tad unstable so hopefully this won't be a problem. We're just going to go for it.

Melissa Rosen: We're going to keep our fingers crossed. Listen, can we begin by acknowledging that this can be a difficult conversation. There's a real stigma surrounding this topic. There can be embarrassment, for some even shame and it's complicated, right? There's physical issues, there are emotional concerns. So perhaps the best way to deal with this is simply to jump in and start a conversation with some questions. How's that?

Dr. Bat Sheva Marcus: I think that's perfect. And I want everybody listening to understand that this is such a tough conversation for everybody, so it's not just for cancer survivors or people with cancer, sex is just hard for us to talk about, Melissa. It just is hard and I always hope that we'll move into a world where it's easier, but let's try to make it easier.

Melissa Rosen: That's right. Absolutely. So at the most basic level, does a diagnosis of cancer mean the end to your sex life? And if not, why does it feel that way so often?

Dr. Bat Sheva Marcus: That is the quintessential question. And no, the answer a hundred percent, a thousand percent, and I sort of start to tear up as I say this, which usually I cry later when I'm talking, but not this early. But I just want everybody listening to hear me say this, a diagnosis of cancer does not mean the end of your sex life. It will mean some challenges. It will mean some challenges, but so many things that happened in our lives also present us with challenges. And in almost every case you can overcome challenges. That's why they're challenges, they're not the ends, they're not the end. So I think sometimes people lose sight, especially people who are struggling with cancer or have trauma from having had cancer because they feel like it's sort of the death knell to their sex life.

And I want you to hear now from me that that is just not the case. That so many people struggle in so many ways with their sex life. People who end up with other physical ailments, just as we age things change. And that the more you can recognize that your sex life in every situation is going to hit road bumps. And cancer is a road bump, it's a big a road bump. I'm not making light of the fact, but it is a road bump and there is always ways around those road bumps and we'll talk about. And some of those road bumps are actually physiological, they're medical and they need to be addressed. And some of those road bumps are psychological and are about feelings about ourselves and how it impacts on our relationship. But I do feel like if you start with the assumption that nothing's going to help, it makes you feel very unempowered and that is not a useful way to head into your sex life.

So what I would say is say to yourself this, "Maybe my sex life is not working for me now." And that is honestly true about so many people who don't have cancer also, right? I have an entire practice that's just full of people who are coming in constantly saying, "I have no desire for sex. I have trouble getting aroused. My orgasms aren't what they used to be. I have pain with it. Oh my God, I have pain with sex." All of those people, they have it also. So the fact that you are struggling with either cancer or the treatments from cancer that have created some of these problems makes these problems sort of highlighted for you, but they are not insolvable and that's the most important thing for you to know and remember.

Melissa Rosen: That's a very hopeful way to start this conversation. Thank you for setting that tone. So what are some of the most common concerns that cancer patients might face and how might we approach some of these concerns?

Dr. Bat Sheva Marcus: Okay, so that's a huge question Melissa. So why don't I break it down a little bit and then you can decide where you want to go with it, how's that?

Melissa Rosen: Okay.

Dr. Bat Sheva Marcus: Okay, well where are the people listening? Want to vote in, we could just do a little ballot. So pain is a big one because people who have vaginas, pain, but it's pain with intercourse. And I could talk, oh my G-d, I could talk for an hour and a half about how distorted our view of sex is when it's so intercourse based. When we talk about intercourse being penis and vagina, sex does not have to be penis and a vagina. There's a million other ways to have sex with your mouth, with your hands, with your toys, with feathers, with your breasts, with your ass, there's a million other ways to have sex that do not involve a penis and a vagina.

But for many, many people, especially heterosexual people that has been sort of the basis of their sex life. And so the vagina in particularly is extremely hormonally mediated and it's going to be the first thing to feel it when your hormones are off. And truth is perimenopausal and menopausal women who don't have cancer have very, very similar issues as women who have been diagnosed with cancer or have been treated for cancer. And therefore their vaginas are just in a different place, but it can be treated. And I am happy to talk about how to get your vagina back on track because for a lot of people that's really an important and central part of their sex life. So that's issue one. Issue two is because of all theirose hormonal shifts that are happening, people's desire drops. Their desire to have sex drops and their arousal, their ability to get turned on drops. And arousal and desire are separate things. And we can talk about how they're a little bit different. They play off each other all the time, but they are different.

But that could be because of dramatic hormonal shifts. Also again, I will say to you, perimenopausal women and menopausal women very often come in with the same complaints. I'm just not interested in sex anymore or my body doesn't respond. I'm not getting wet. I'm not getting turned on. I can't get that laundry list out of my head. I still keep thinking about making the kids peanut butter and jelly sandwiches even though I want to be thinking about the hot person in my bed. So there's those pieces of it. And then sometimes our orgasms can be affected both by the hormonal issues as well. Now I'm going to layer on top of that. And again, these are not unique to cancer patients, but they're important, which is our sense of ourselves has changed.

Our comfort level with our bodies. Some of us have had surgeries on our bodies and we don't necessarily feel as attractive or as sexual beings as we used to once upon a time. Our relationships shift also because some of us go from being these like very competent, capable people and we're still competent, capable people but we need to help in ways we may not have needed help at other times in our life. So all of those things are playing into your sex life. And again, I want to say to you, these things play into a lot of people's sex lives, not just cancer patients and cancer survivors.

But they can be extremely sort of overwhelming when they sort of hit you all at one time. And more than that, I feel like it's hard to have a roadmap to how to get yourselves out of this. You feel like you're mired in this plate of spaghetti is the way I often talk to my patients. They come in and they dump this whole plate of spaghetti, their sex life isn't working and my work with them to pull out the strands and figure out, okay, what's actually not working. And where can we get you help.

Melissa Rosen: So that seems a little bit to me like a chicken and the egg. All right. So you have the physical things, whether it's a change in hormones or a surgical change, you have the emotional things,

whether you're overwhelmed by cancer or you're not comfortable with your own body. And so those lead possibly to diminished desire and arousal and some physical pain. Which comes first when addressing it to get a sex life back on track?

Dr. Bat Sheva Marcus: So I have to say, I think they work together. I think that we have created a false dichotomy in our society between the brain and the body. We just have. The study that I love to quote because it always sort of opens people's eyes as a study that came out I don't know, a few years ago, the *New York Times* did it on men and testosterone. So these were men who stayed home with their children who chose to stay home with their children and their testosterone levels dropped. Think about that. Their behavior affected their hormone level. So we get sometimes that our hormones affect our behavior level. I cannot number of women who come in who say like, I'm just not very interested in sex anymore, I'm actually uninterested in sex and it's hormonal.

And they're like, but it can't be hormonal because it's the way I'm thinking about it. And I'm like, what do you think makes you think about it? So the analogy I often like to use, and this also sort of gets people to understand kind of where this interplay is, is if you see two 17 year olds waiting in line or on the bus. Let's say you see two 17 year olds on the bus together. This is kind of pre COVID but anyway, and they're climbing all over each other. They can't keep your hands off each other. If you're watching this and you're thinking to yourself, oh my G-d. Do you start thinking to yourself Melissa, they must have had a truly meaningful conversation. No, that's not what you think. Or he must have done the dishes or he must have bought her flowers.

You think their hormones are raging. And legitimately that's what you think. And yet when it comes to people who've been through cancer treatment, or let's say, perimenopausal women, somehow we're uncomfortable saying, oh, maybe the hormones are the problem. So I think they work together. And I think that what I often will say to patients is let's start working on the things that you feel comfortable working with. And if you kind of get stuck, so let's say we decide to try to work on your fantasy life because I think that's a good thing to talk about because that's very practical, it's easy, not so easy maybe but we'll talk about it. But if you get stuck, I would say to you, yeah let's take a look at your hormones. So when you look at desire, when you have problems with desire and arousal, I would say my bias a little bit is towards the physiological, towards the medical.

Only because I feel like as a society we have put so much emphasis on the psychological and the relationship. So if a person comes in and says, my sex drive is plummeting, they're so quick to say it must be my relationship. And I'm like, well, but you've been in the same relationship for 40 years. I get you're a little bored but you were bored 20 years ago too. And it's a pretty good relationship as you're describing it to me, there's nothing terrible happening in the relationship. Nothing dramatic has changed but you get your level of desire for sex seems to have gone down. And so let's not go through a rabbit hole of two years of counseling before we figure out whether or not there is something physiological going on because sometimes the lack of sex creates the problem in the relationship or the two years of digging at the relationship to figure out what the hell is the matter creates the problem in the relationship.

So I think Melissa what's really, really important for people to realize is that there's a complicated interplay. And I think most people are extremely smart about figuring out. We tend to go towards the psychological just because that's what we've been told and that's what our gut reaction is. Oh, it must be the relationship, it must be. But I'm going to tell you, if you're working on that, you shouldn't have to work so hard, you shouldn't have to work. You should be able to work a little bit and have results. And if you're not, then I say let's look at the physiological, let's look at the medical. The exception to what I'm saying is really any pain. That is not psychological. I mean if I have to like stand on

my head and say it 53,000 times, if the doctor says to you, I don't see anything therefore it must be in your head.

I'll tell you what you should do. You should leave and you should find yourself a new doctor because just because they don't see anything does not mean that the pain is psychological. And I've been quoted often as saying and it's a hundred for the truth that when somebody says to me, I've been seeing a therapist for six months for my pain and my therapist says your vagina is trying to tell you that you're not ready to have intercourse. I'll be like, nope, your vagina is telling you that you need to find a new therapist. So go out and find a new therapist. So pain is the one exception where in 99.9% of the times it really is medical. That doesn't mean that there aren't psychological implications that have to be addressed but it really is medical. And I think I just gave you an extraordinarily long answer to a very short question. So I apologize.

Melissa Rosen: No, no, it's good. And led to lots of other questions in my mind. So can you just elaborate with regard to cancer specifically or cancer and in the cancer treatments, what are some of the causes of the pain and what can be done about it without undermining the treatment?

Dr. Bat Sheva Marcus: So the biggest, the biggest, biggest, biggest factor here is that in many cancer treatments they're trying to get rid of your estrogen. That's like easiest way. They're trying to eliminate estrogen in your body. Your body needs a certain level of estrogen to function the way you're used to it functioning. And if not, you got to figure out ways to manage without it and we'll talk about this. Your vagina in particular, if you have a vagina, your vagina in particular is incredibly hormonally mediated. It means it's the first one, the first part of your body to feel it when that estrogen dries up. So that is the most, most common thing. The other thing that the hormonal changes do is it can kill your ability to the other three, the triad, arousal, orgasm and desire.

It makes it harder for you to want to have sex. It gets harder for you to get turned on when you have sex. And again, makes it harder to have an orgasm. However, the good news is those three are a little more intrinsically linked to testosterone than they are to estrogen. So let's go back to the vagina for those of you with the vagina. So let's go back to vagina. First of all, more and more physicians are getting comfortable with use of local estrogen in your vagina. Now for people who don't understand the difference. And I outline this quite clearly in my book because I feel like this gets so confused. Systemic versus local estrogen. There's estrogen that's meant only to stay in your vagina and vulva area, clitoris, vulva, vagina, that whole area. Then there's estrogen that's meant to systemically circulate throughout your body.

Most, most cancer treatments wants to get rid of the circulating estrogen. That's most cancer treatments. Some of them really want to get rid of local as well. And this is really where you have to talk to your doctor. But what we have discovered at our center is that more and more oncologists are comfortable using local estrogen, using local estrogen especially because more and more local estrogens are coming in, in smaller dosages. So there's a product called Imvexxy. I don't know if people are familiar with Imvexxy, I get no money from, I want you to know, I'm getting no money from any product. So I just want to be really clear about that. Imvexxy is now coming in at a 0.4 which is about half or a third of sort of the classic estrogen products that you would normally insert into your vagina, like Estrace and whatever. And so doctors are much more comfortable with that.

However, if for whatever reason either you or your doctor are totally freaked out about the idea of using estrogen locally, there are really good alternatives to make your vagina feel better. So one of them is hyaluronic acid which you may be familiar with. Again, I do outline all this stuff in my book because I feel like I'm going to be going through a lot of stuff very quickly. Or even I think our website, the Maze women's website may have it, I'm not sure. But there are a number of over-the-counter products. So the worst thing to do is to think that by adding lubricant you're going to solve your

problem. I just need to say that like, that's where everybody jumps to. Oh, my vagina's dry and it's like, it's like. What happens is if you look at your vagina it gets very thin and like tissue papery.

So lubricant is not going to do anything. I mean, it's going to help a little because it's going to put something wet in your vagina for a few minutes but it's not going to help that tissue in any way get better. That's the problem. It's not going to make it plumper. So either a hyaluronic acid works quite well and there's a product called Revaree out there which is really good. And those you can buy, you can buy them over the counter, not super inexpensive but very effective. And it's the same hyaluronic acid you use on your face. It's great, hyaluronic acid is amazing. Anyway, but it's for specifically meant for your vagina. And then there's a laser called the MonaLisa and the FemiLift, I think is the other one called. We have the MonaLisa, we don't have the FemiLift but I think they're pretty much the same.

And they do, it's fascinating. They basically go in, they don't hurt. I want to just say, they don't hurt. They sometimes are irritating the day after. And everybody's like, oh my G-d, a laser in my vagina. Like it really doesn't hurt. Basically it goes in and it sort of attacks or destroys, I know that sounds terrible the mucosa or the skin on the inside of the vagina. And it says to it, you need to repair, you need repair. And so the vagina creates new mucosa. So it's pretty cool. It's two or three treatments.

It is of course not covered by insurance but we can have a whole conversation about women's health and insurance coverage but it is a fabulous, fabulous alternative for women who don't want to use local estrogen. So that is my speech about products that you might want to consider for your vagina. And I would say to you, if your vagina's [inaudible 00:23:38] you might just, even though you can have great sex without using your vagina, for most women it just feels yickey to have a vagina that doesn't feel good. And there's another thing people might want to consider which is moisturizers, vaginal moisturizers which is different than lubricant. Lubricant goes, am I talking too quickly Melissa?

Melissa Rosen: No, you're good. There's a lot of information to cover.

Dr. Bat Sheva Marcus: I have a tendency when I get excited to talk really, really, really fast.

Melissa Rosen: That's one of the reasons we record it. So people can go back and use the recording as a resource.

Dr. Bat Sheva Marcus: In half speed, you can listen to me in a half speed. It's great. OK. So so yeah. So what was I going to say?

Melissa Rosen: Moisturizer, vaginal moisturizer.

Dr. Bat Sheva Marcus: Right. So the moisturizer is not going to fix the mucosa in your vagina but it may make you feel wetter. And for some women that's actually quite helpful. It just makes them, you can use moisturizer every single day. It won't do anything bad. It just makes you feel just moisture in the area, in the vagina. And what's kind of cool, I have discovered is it's a little, what we call reverse Pavlovian response which is that you know how when you get turned on, you get wet. So sometimes when you're feeling wet, you're like, oh, I could get turned on. And it works quite well for it. Over the counter, easy to handle. So that's talking about the vagina and the pain with the vagina.

When we're getting into arousal, orgasm and arousal, orgasm and desire that is where testosterone can be super duper helpful for women. And more, again, more and more, more and more physicians are fine. And once upon a time, like 15 years ago when we started this I would say medical professionals were nervous about testosterone because they thought it might convert into estrogen. We see very, very nominal conversion into estrogen. We keep a good eye on bloods but it can have a dramatic impact on all of those what I call quadrants. Because in my book I have four quadrants like pain, arousal, orgasm, desire. So on those three quadrants, it can be super duper helpful, testosterone.

I would just hazard anybody watching and thinking about it then you go to somebody who actually really knows what they're doing, keeps an eye on your blood levels. There are other... And it's a long term project, it's like a six to eight month project to see if it works, but it works quite well. You can use it as a cream. There's a pellet that can be inserted. Testosterone is, I am a huge testosterone fan. I feel like when you think of testosterone as a male hormone but women have it and need it. And that's another one by the way which is not unique to you guys, cancer people like as women get older, their testosterone drops. You're just catapulted into that unfortunately. So more and more. And there's actually really good data now in terms of cancer risks with testosterone.

And Melissa if you asked me after this, overall I'm happy to give you a meta-analysis that was done a number of years ago on that because I think it's really interesting. So now also there's a few other products that have recently gotten FDA approval for women's desire. One is called Addyi and one is called Vyleesi. I feel like they're good, they're not as effective, but there's something to think about. Again, I talk about all this in my book and you could do a little research on your own if you're interested in that or any sexual health medicine doctor will be able to help you with that.

Melissa Rosen: A question came in. In addition to these over the counter things, some of the procedures like MonaLisa and medicines that can be prescribed, are there other things like maybe pelvic floor exercises, does that impact at all?

Dr. Bat Sheva Marcus: When you're talking about pain, vaginal pain with intercourse, it does. Whoever ask that, you're very smart. But it's the secondary issue. So what's being caused by the cancer treatment is generally this sucking out of all your estrogen. I mean that's often the case. But what happens is as soon as the muscle, either because, we're not sure why this happens, but either because it starts to be a little painful and so people clench their muscles or just because the estrogen was keeping the muscles and the skin, everything kind of lubricated and now it isn't, things are tightening up. What happens is the muscles tighten up and that can cause a different kind of pain. It's a pain that's called sort of in the vernacular vaginismus. Which vaginismus is like exactly that, the tightening up of the muscles that nothing can get in there or you could get something in, but it just hurts when you put it in there.

Pelvic floor physical therapy can help with that. So pelvic floor, I love pelvic floor physical therapists. I think they're angels many of them. I will say to you, if you think that's what's happened to you and you don't want to get started with pelvic floor physical therapy, which can be very extended, you could just buy dilators. There are these things called vaginal dilators they're easily purchased on the internet. They come in different sizes and you can just insert them. Some vaginismus patients, young women who've never had intercourse are petrified so they have a hard time using those dilators. But for most of the women who are watching here, people with vaginas who are watching, you're not scared. You're not scared other than you know it's going to hurt legitimately. So using a good moisturizer lubricant and using those dilators can be unbelievably helpful.

And those dilators are often used by physicians when they've done treatments that actually have resulted in the narrowing of the vaginal canal. And so they want to kind of re-stretch it. And all that does is help you re-stretch. Because just for people to understand, your vagina is not a tube. It's not a hole that's there. It's a potential space. It's muscles that go in and go out and so you have to teach the muscles not to clamp down. Just like you do learning to do as a split. And you wouldn't like push the person down into a split immediately, that sounds horrible. So slowly but surely you want to be able to use those muscles.

Melissa Rosen: That's a good way, potential space is a good way to think about it. I saw a question come in. One of the things you talked about in this last answer was vaginal moisturizers and a couple of people were asking for product recommendations.

Dr. Bat Sheva Marcus: Those are all over the counter and so I can't tell you, I feel like I would look for reviews. But be to be honest with you, with lubricants and vaginal moisturizers, lubricants I can probably tell you liquid the silk or slick liquid seem to be super and coconut oil. Coconut oil is awesome. Can I just say coconut oil, I was just talking to one of my therapists and she's like, "I was just talking to a patient who uses coconut oil for everything, my face, my vagina, everything." Anyway, so coconut oil is great. But the thing is about both lubricants and vaginal moisturizers is it's very personal. It's a little bit like your shampoo, you don't want to get in an argument with a woman about my shampoo's better than your shampoo. Like everybody's different. So yeah.

Melissa Rosen: OK. That's good to keep in mind. So I'm sort of now flip flopping between questions we got at registration and some of the like more global questions. But one the thing that strikes me as part of some of the questions we got that might be appropriate now is is there ever a point of no return? If somebody's been through treatment, they've stopped having intercourse, penetrative intercourse because it was painful, there's little desire. Like after a certain number of years, is it too late?

Dr. Bat Sheva Marcus: No.

Melissa Rosen: That's good.

Dr. Bat Sheva Marcus: It's never too late. Now I said to you I always tear up at different points. Like now I'm like, it is never too late. It may take more work. It may take more work and more concerted effort. And I think what you need to understand is that our brains are very plastic. Neuroplasticity is something we're starting to understand. And when you shut down a part of your brain, if you shut down all the circuits that were involved in pleasure, a certain kind of pleasure, it is hard work to turn those circuits back on again. I'm not going to pretend it's not, but it a hundred percent can be done. Melissa. And whoever wrote that question, I want I'm with you. It is doable. It is totally a hundred percent doable. You have to figure out your entry point.

And so if you are, that's what I said, for a lot of people the entry point is their vagina. They just want their vagina to feel better and stop hurting. And so for a lot of people that's kind of a easier and concrete way to go in. For other people, and so I'm going to jump back to fantasy right now because I feel like that's probably the quintessential place where so many of us shut down a part of our brain. And I think we all do it. And the more sex is a struggle or the more that we have other crises happening in our life, the less we go to that part of the brain. And yet we know that those parts of the brain can come alive again. If you're good at languages and you just do not use any foreign languages for a bunch of years we know what happens in the circuitry of your brain.

It shuts down, it just stops. Those neurotransmitters are like, oh, we're on vacation. Your brain is not going to waste effort on sections of the brain that it's not using. And so the neurotransmitters stop blinking, basically there's less synopsis going off. There's just no activity in that part of the brain. And so that means that you have to do the work to get that part of the brain functioning again. But once you start learning languages again, it's really hard work in the beginning to get that French up and running but then the German becomes easier and the Italian gets even easier. So what I would say is I will often say to women, connecting with your fantasy life is really a good entry way and a way to start because so often people say, well fantasies those should happen naturally.

Well a fantasy is something that happens naturally and I'm going to be like yeah, it happens naturally for those 17 year olds we were just talking about on the bus. They have lots of, lots of spontaneous fantasies. Not so much for many of us. And certainly not people who've been through the trauma of a really difficult illness and or just life, busy, crazy lives where other things take priority. So I will highly recommend that people start working, working on their fantasy life even if that sounds insane. And that may be by watching some erotica, reading, I feel like women connect to written erotica much more than they do to other forms. I mean I could say I think that but that data shows it front, left

and center. Women do not go so much to classic porn sites but literal erotica, which is a written erotic site has billions of women on it for long periods of time.

There's now audio erotica. There's a white website called Dipsea, sort of an app called Dipsea which has actors reading erotic stories. And it feels really uncomfortable when you start kind of digging into this, you want to get it into your brain. You want to eventually be able to just create things in your brain. But in the beginning you may have to use external forces to do that. And if you start finding that, it's really hard to do that, that's where I say look at the testosterone because the testosterone's going to help that part of your brain come alive basically is to what's going on. So never, I would say never give up. I mean never ever give up with a caveat that if you don't care, like I often hear people say, no, why should I care? And I'm like, you don't have to care. If you honestly do not care about having a sex life, then that's fine.

You're not going to die for not having a sex life. By yourself, even by having sex by yourself and I'm talking about single people here as well. Sex for one is a fabulous way to have sex frankly, a lot less pressure. You always know when you're in the mood, you're the best, best possible partner you could have. So I would say, if you're not partnered and you sort of feel like, well, is it worth the effort? Then I would say you have to make that decision. But my experience is that people feel more alive and more whole and more who they are and happy when they're connected to their sexual self. And I have to assume that anybody who came onto this webinar is sort of feeling like that's something that they want in their life.

And we know that sex, when you're partnered, sex is important, it's just like an important part of your life. And I will have women, women will often say, they'll even use almost the same language to me which is always amusing. And they'll say something like if I come home and I see my partner's socks on the floor and we haven't had sex in a long time. I will scoop them up and I want to stuff them down his or her mouth, I'm so angry. But if I come in and we've been having great sex, I sort of laugh and I pick them up and I dump them in the hamper. So I feel like what happens, sex is so important in relationships because it changes the tenor of the relationship and that's with ourselves as well. So I'm your biggest cheerleader. I believe everybody, I don't think anybody's too far gone. I do not believe. I've worked with women who are 72 who had their first orgasm. Like I do not believe you are too far gone.

Melissa Rosen: Okay. That is another piece of encouraging information. So can we just talk for a second about, and something you just touched on about how relationships are impacted when there is no physical sex. And that's not, I'm not even talking about like different drives and one partner wants it and the other partner is uncomfortable doing, I'm just talking about when there's little physical sex in a relationship, how does that impact the relationship?

Dr. Bat Sheva Marcus: So the data suggests that relationships are better when there's a sexual component. And that is not to say, and I don't want anybody to get off here and saying Bat Sheva said it's impossible to have a good relationship without sex of any sort. I'm not saying that's true. And there are, I have seen couples where that's the case. But for the most part sex can work as the glue in a really important way in a relationship. And one of the things that I think I watch happen when there's illness is that sex gets put on the back burner and then nobody's quite sure how to pull it back to a front burner. And that's where how do you make a habit. And the partners of the people who are ill feel guilty for wanting to have sex. They feel like somehow it's not okay for them to want to have sex.

And for sometimes, especially if we're talking about let's say a woman who's faced cancer and then she's married to a man. For many men, they feel like they've lost two things. They've lost the sex and they've lost the physical contact because the woman and will say, well every time I try to just kiss him or hug him he understands that his mind wanting to be willing to have sex and I'm really not up for that yet. And so often partners of people who are facing illness will be feeling like a double loss as will

the person who's facing the illness themselves who feel like they don't have the physical, they're not getting the physical comfort they want because it's too treacherous waters because they're afraid that they have to deal with the sex. And I feel like the best way to handle that is to talk about it.

I feel like that feels to me like the kind of thing that a conversation needs to be had. What can we do in the meantime? What are you up to doing in the meantime? What are you willing to do in the meantime? What would you like to do in the meantime? What would be meaningful to you in the meantime? And that conversation should be had kind of regularly because that will shift. I really think Melissa, like it's not like it's from today to tomorrow the same thing. But I will say, there's a wonderful movie, which I'd highly recommend people watch called Hope Springs, Hope Springs. Not to be mixed up with Hope Floats. Hope Springs with Tommy Lee Jones and what's her name? Oh my God. Miranda Priestly, you know her name. Meryl Streep. Meryl Streep. And I'm happy to go wrong with Tommy Lee though but it's about a couple who hasn't had sex in a very long time and they have to sleep in separate bedrooms and the woman just feels like she's feeling so lonely. She can't handle it anymore. And so it's a little Hollywood, I'll give you that. But what I love about that movie was it showed the tenor of the relationship, the playfulness, the way the shift of the relationship when you put the sex back in. Melissa, I'll always say to people I'm not in this field because I'm so fascinated by putting body part A into body part B. What's meaningful to me is what shifts in a relationship when you put sexuality back in. And I said it's about yourself as well. There's something, there's something elemental and real about sex and our sexual selves. And when we're sort of not in conversation, not able to be there with our sexual self, it just changes things. And that's true about our partners as well.

Melissa Rosen: Okay. I just took a look at the clock and so I could keep talking like this forever but there were some participant questions that I think are really important to get to. Please, if you're on this webinar and you've asked a question, listen for the themes and ideas because many of the questions were very similar and focused around a few things. First, before I go into that, I saw somebody posted in the chat box about vibrators and the dilators, the dilators. Who would you talk to about that? Would it be your OB/GYN, your oncologist, a sex therapist?

Dr. Bat Sheva Marcus: So the dilators, you can definitely talk to your oncologist. And I just saw a note, please speak slower. I'm trying. Okay. So the dilators, you can definitely speak to your oncologist about maybe your OB/GYN, the vibrators don't bother. They're not going to have a good conversation with you. But I will give you, I have a free three part course on introduction to vibrators on Maze Women's Sexual Health. If you go to Maze Women's Sexual Health and you look up orgasm, or it's somewhere around there, you'll float around, just look vibrators. I did a three part video series specifically as an introduction to sort of demystify the whole thing for people. So I'm having the book too, but that is more fun. I think the course is more fun.

Melissa Rosen: Okay. So let's get to some callers questions. So a lot focused on reclaiming sexuality and self-esteem and the interplay between self-esteem and sexuality, especially as you alluded to earlier, many of our bodies are covered in scars or were missing parts, particularly parts that were integral to our sex lives prior to a diagnosis. So how do we start to reclaim our sexuality personally? And then if we're a partner, to bring it to the partners, and is there a way to start slowly and not just jump right back in?

Dr. Bat Sheva Marcus: So I feel, I'm very practical and I feel like the most effective way that I have seen working for my patients is self-talking. Is sort of a combination of finding sort of what I'll call hacks and self-talking. So that may mean finding some really pretty lingerie or a nightgown that you just think is really fun. That covers you up to start with. You may not be totally willing to be a hundred percent naked with your partner again until you get more comfortable with yourself. And I feel like talking to yourself in the mirror, it sounds so hokey, but I feel like it is so empowering. Get naked in front of the

mirror or uncover one part of your body let's say it's your breasts. And say to yourself, my breasts, my skin is so beautifully white.

Do you know what I mean? Like my smile is amazing. And I'm beautiful. You have to realize to a certain degree that our bodies, they're so bizarre, regular bodies. It just that we're used to them. If a Martian landed here, they wouldn't see a difference between a body that had surgery or a body that didn't have surgery. I think they'd see a difference but they wouldn't necessarily intuitively think that there was one more beautiful than the other. This has to do with our societal norms which are so deep. I really don't want to minimize them at all but I do think that exposure, talking to yourself and finding things to wear that makes you feel beautiful are really incredibly helpful.

And let's go back to the talking to your partner piece because I think in a lot of cases, your partner, you need to listen to them. I cannot tell you how often I'm in the room where the partner says, but I think she's beautiful and she feels so broken. And I'm not going to minimize, I think it's really important to have a therapist here to work through some of these issues. But if you can allow your partner to, listen to your partner and hear what she or he has to say, it can be very healing.

Melissa Rosen: That was great. A couple people asked, how do I find a doctor or a therapist who specializes in this? Obviously now they're aware of you but people are across the country on this webinar. Is there a website that lists them or something like that?

Dr. Bat Sheva Marcus: So there's the International Society for the Study of Women's Sexual Health which lists therapists and physicians that deal specifically with sexual health. And they should all be able to deal with post-cancer issues as they deal with many other things. I will say this, when you look on psychology today to find a sex therapist I'd be wary about anybody who has a lot of specialties. If you do a sex therapy and you're one or two other things like couple's therapy and sex therapy. But if you do sex therapy and EMDR and eating disorders and child psychology, I'd be wary of that. There's another organization called AAASECT, American Association of Sex Educators, Counselors and Therapists and they also have a listing of sex therapists who should be able, you can look through and you can. And I would say, be brutal. I'll often say to people, when you're looking for a therapist, make three appointments, make three. It sounds like a waste of time and money, but at the end of those three appointments, you will say, oh my God, I really connected with this person. I feel good about this person. As opposed to well, maybe, it seemed like it was okay. And so invest in yourself because you're going to end up seeing this other person 10 times, 15 times, 20 times, it's worth the upfront investment.

Melissa Rosen: Thank you. And by the way, somebody asked to repeat the information. It was just put, the name of the organization was just put in to the chat box. Okay.

Dr. Bat Sheva Marcus: So that was the ISS- that's ISSWCH, that's the doctor. And then there's AAASECT, American Association of Sex Educators, Counselors and Therapists, separate organizations.

Melissa Rosen: Okay. Thank you very much. Okay, couple of very specific things that we didn't get to. Somebody asked about recurrent UTIs since treatment every time she has intercourse. Is there something that can be done preventatively as opposed to treating it after?

Dr. Bat Sheva Marcus: Well sometimes it's because the vagina itself is just so dry and irritated. And so things end up moving into the urethra that shouldn't move into the urethra. So sometimes just like the MonaLisa could possibly be extremely helpful here. Other than that, what they do is they give you antibiotics preventatively. And probiotics, big thing, probiotics guys. Start paying attention to there's probiotics that are put out specifically for your vagina. The same company that makes the Revaree that I talked about makes a probiotic to the vagina. That would probably be very useful as well.

Melissa Rosen: Thank you. Somebody just put in the chat box now, is it okay to have sex during treatment chemotherapy?

Dr. Bat Sheva Marcus: I don't know the answer. I'm assuming it is but that you have to talk to your oncologist about. I don't see why it would not be okay but definitely talk to your oncologist but go you.

Melissa Rosen: Absolutely. Somebody asked again about MonaLisa. So in one sentence can you just explain what it is one more time.

Dr. Bat Sheva Marcus: It's a laser that is used. It's a probe that gets put into your vagina. It's about a 15 minute procedure and it doesn't hurt but it basically uses these beams to destroy essentially the vaginal mucosa so that it rebuilds. It tells it to rebuild a new set of vaginal mucosa. So you use it, it's like two or three treatments and then you usually need some kind of booster every year to year and a half, two years, depending on your vagina.

Melissa Rosen: Perfect. Somebody else asked about the particular challenges for people who are living with metastatic cancer. Treatment may not end, things like that.

Dr. Bat Sheva Marcus: So I think that, I honestly think the challenges are probably not that different, just more, there's just more of them and it's scarier. And that is the situation where I'm sure people in this situation have told you, or whoever's asking this question that I really do feel like therapy, sort of figuring out what your priorities are. What do you want? It feels to me like, right, you need to figure out like what do you have bandwidth for and what do you want? And what will your doctors allow you to use? Because you may say I don't want to deal with intercourse right now and that's fine. I don't know that the challenges are fundamentally different other than they just feel to me like they're just stacked on top of each other. Melissa you could help me if I'm wrong because that is sort of where it feels like to me.

Melissa Rosen: Obviously everybody's different but that seems like a good assessment. We have time for two more questions. So somebody asked about using post-treatment post-active treatment, a libido question. Wants to know if other there things, they've tried antidepressants like Wellbutrin and things like that. They've tried switching aromatase inhibitors, acupuncture, taking a vacation from the aromatase inhibitors. Is there anything new besides that approach? You mentioned testosterone as a potential option. Anything else?

Dr. Bat Sheva Marcus: Yeah. So there's a product out there called ADDYI. Furthermore, Wellbutrin's not going to be useful for desire just for everybody here. Wellbutrin's actually quite useful for arousal and orgasm. I explained this more in my book but I will jump into that. But I know people that does draw well, I love Wellbutrin, amazing drug but it just doesn't help for desire. Testosterone can be unbelievably helpful number one. As I said, there's two drugs out there Vyleesi and ADDYI. Both of them are approved for desire. I actually think ADDYI it's a daily drug, it's similar to an antidepressant but it's specifically meant for desire. And then there's Vyleesi which is used. It's an injection, it doesn't hurt. It freaks everybody out. It's an injection you use and use it right before you have sex, before you have any kind of sex. And both of those are recently approved. So my first go to honestly would be testosterone. And there's another over the counter one called Ristela which seems to have some efficacy as well. But those are like, again, testosterone is super duper helpful. Ristela, a little helpful. ADDYI, a little helpful, Vyleesi, a little helpful.

Melissa Rosen: Would all of these things also help not just with design but like intensity of orgasm if that's been diminished?

Dr. Bat Sheva Marcus: So Vyleesi, which is the shot, would affect intensity of orgasm. Wellbutrin is super duper helpful with intensity of orgasm. Testosterone is super helpful with intensity of orgasm. There are definitely options. But they're much more subtle. As well testosterone truly, I don't know how to say this in a nice way, but testosterone really works and the other ones are just more subtle.

Melissa Rosen: Okay, okay. All right, last question. It's more like I'm asking you for a parting thought. Somebody talks about how their cancer diagnosis and subsequent treatments has truly deeply impacted the way they feel about not just sex and sexuality but gender. And I just wonder for people who are struggling to feel either feminine if that's what they're looking for or just to feel more like themselves again, what parting thoughts do you have?

Dr. Bat Sheva Marcus: Whenever you hit a severe illness it makes you reevaluate your life. I mean I think it makes you reevaluate who you are and how you move through the world. And some of that is for some people that's going to hit on the gender, on the gender, the part of themselves, that's gender. For some people it'll hit on the relationships that's why relationships often. For some people it hits on the careers and what they want to do with their lives. What I would say to you is this, the most important thing about your sexuality is that it's unique to you and it doesn't have to belong to anybody else, it just has to be you. Which is why I struggle a little when people use a lot of labels like bisexual and sapiosexual and parasexual because in the end, I'm just Bat Sheva sexual and Melissa, you're just Melissa sexual and that's kind of the way it should be, right? What I like and what I want to think about and how I want to move through the world is just mine and how you do you is yours. But I do believe all of us should be able if possible to connect to our sexuality. That means that we can connect to sexual pleasure, to orgasm if that's what we want. To being able to think sexual thoughts and they don't have to fit into a box of any sort. And so maybe a good way to look at this is that this is a time that you get to explore and be a little different and sort of reevaluate. And maybe that could be a really lovely, maybe as you're moving around your road bumps, you'll find a new pathway that really brings you to some special places.

Melissa Rosen: I love that. Listen, we could talk for so much longer but we're already a few minutes beyond where I wanted to take a pause. The first thing Bat Sheva, thank you so much for sharing your expertise. I learned so much today and I hope all of you did too. For ongoing information on the topic we absolutely recommend that you follow Bat Sheva and Maze on Instagram and check out their website. Links to both are in the chat now. And right before we started, Bat Sheva said she answers a lot of questions on Instagram. So if you have questions, that's the place to go. Once again, thank you to Maze Sexual and Reproductive Health and to Merck for supporting this important program and Living Beyond Breast Cancer and NYBRA for their community partnership. There is also a link to a brief evaluation survey on today's program. It's linked in the chat box right now I see it. Anyone who completes the evaluation today will be in the running to win a copy of Dr. Marcus's book. Please remember that Sharsheret is here for you, for your loved ones during this time. We provide emotional support, mental health counseling and other programs designed to help you navigate through the cancer experience. All are free, completely private and one on one. Our, our email and our telephone number will be in there. And listen, I just want to say, as I finish up with the last couple of things, I am seeing in the chat box thank you, thank you, amazing presentations, so helpful. So really everybody thinks so. Okay, we'd love to stay connected with you by social media too. So take a moment to like us on Facebook, follow us on Instagram or Twitter where we post amazing information, some creative things and information about programs that we have coming up. So speaking of programs, Monday night, this coming Monday night we have a program called Beyond BRCA about not only BRCA genetic mutations that raise diagnostic risk for cancer but other ones and what they mean to us individually. And in January we're planning among others two great webinars. One is creating survivorship care plans which could include addressing sexual health with your healthcare team. And the other one is our next Sharsheret in the kitchen on cancer nutrition. From all of us at Sharsheret, thank you so much for joining us today and have a wonderful weekend. Thank you Bat Sheva.

Dr. Bat Sheva Marcus: Thank you.

About Sharsheret

Sharsheret, Hebrew for “chain”, is a national non-profit organization, improves the lives of Jewish women and families living with or at increased genetic risk for breast or ovarian cancer through personalized support and saves lives through educational outreach.

With four offices (California, Florida, Illinois, and New Jersey), Sharsheret serves 150,000 women, families, health care professionals, community leaders, and students, in all 50 states. Sharsheret creates a safe community for women facing breast cancer and ovarian cancer and their families at every stage of life and at every stage of cancer - from before diagnosis, during treatment and into the survivorship years. While our expertise is focused on young women and Jewish families, more than 15% of those we serve are not Jewish. All Sharsheret programs serve all women and men.

As a premier organization for psychosocial support, Sharsheret’s Executive Director chairs the Federal Advisory Committee on Breast Cancer in Young Women, Sharsheret works closely with the Centers for Disease Control and Prevention (CDC), and participates in psychosocial research studies and evaluations with major cancer centers, including Georgetown University Lombardi Comprehensive Cancer Center. Sharsheret is accredited by the Better Business Bureau and has earned a 4-star rating from Charity Navigator for four consecutive years.

Sharsheret offers the following national programs:

The Link Program

- Peer Support Network, connecting women newly diagnosed or at high risk of developing breast cancer one-on-one with others who share similar diagnoses and experiences
- Embrace™, supporting women living with advanced breast cancer • Genetics for Life®, addressing hereditary breast and ovarian cancer
- Thriving Again®, providing individualized support, education, and survivorship plans for young breast cancer survivors • Busy Box®, for young parents facing breast cancer
- Best Face Forward®, addressing the cosmetic side effects of treatment
- Family Focus®, providing resources and support for caregivers and family members
- Ovarian Cancer Program, tailored resources and support for young Jewish women and families facing ovarian cancer • Sharsheret Supports™, developing local support groups and programs

Education and Outreach Programs

- Health Care Symposia, on issues unique to younger women facing breast cancer
- Sharsheret on Campus, outreach and education to students on campus
- Sharsheret Educational Resource Booklet Series, culturally-relevant publications for Jewish women and their families and healthcare Professionals

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