Melissa:

Good evening. Thank you so much for joining us this evening for the second in a series of planned webinars for young women. Today we will be addressing cancer's impact on intimate relationships and sexual health. Last month we explored medical menopause and fertility preservation, and we will include the link to that recording in our follow-up email for this evening's program.

I want to be clear that anyone is welcome to participate in these webinars. This is an inclusive space. Young is in the eyes of the beholder, and relationships come in many forms, single, partnered, married, same sex, heterosexual, all are welcome. As we start, I am pleased to thank the sponsors of this series, Daiichi Sankyo, Pfizer, and the Cooperative Agreement 19-1906 of the Centers for Disease Control and Prevention. Their support allows Sharsheret to continue to offer meaningful programs such as these.

As always, this program is being recorded. No faces or names will show on the recording other than those of the presenters. But if you wish to turn your video off for privacy now, the option to do that is on the bottom left of your screen. You can also choose to rename yourself if you prefer to remain anonymous. You can do that by clicking the three dots on the top right of your photo square. Directions to call into this webinar are in the chat box now.

I'm pleased to remind you that we now have closed captioning available, and instructions on how to do that, how to access them are now in the chat box. We will begin the Q&A session at the end of this presentation with the many questions that were asked as part of the registration process. Of course, you are still able to ask questions. Please place any questions you have in the chat box and we will be monitoring it for them. To send a question anonymously or a comment anonymously, through the chat box, please click on the button that says "everyone," and when you scroll down specifically select Sharsheret. Just Sharsheret, and your message will be visible only to our amazing colleague, Stephanie, who is listed as Sharsheret tonight just for that purpose.

Okay, let's dive in now. Cancer is about so much more than the cancer itself. We of all people know this. Some of what arises is simple to address. Other complications are a bit more difficult, and tonight we're addressing two concerns that fall into that latter category. Before our experts begin, we are fortunate to have Sharsheret caller Emily join us to share her own experiences with these issues. Emily, thank you so much for being here.

Emily:

Thank you for having me. Hi, everyone. My name is Emily. I'm a breast cancer survivor. I was diagnosed with a very rare form of breast cancer in 2019 when I was living in New York City. I actually just recently moved back to California where I'm originally from. After I was diagnosed in 2019, I had surgery and about a month straight of radiation and then was put on Tamoxifen for a total of five years.

I also preserved my fertility in those early, early days, which I know many of us have gone through. And I am now very happy to say that I have two beautiful, wonderful babies as a result of using embryos that we froze back in 2019. So having that as our little "insurance policy" has absolutely paid off. Their names are Miles and Iris and they're wonderful. They're two and a half and six months old, so I am in it if you are a new mom right now.

But as it pertains to this call, when Stephanie asked me if I would be comfortable joining, this is something that I was actually nervous about talking about because I have struggled with intimacy, with my sexual health. It's definitely ebbed and flowed throughout my entire cancer journey. Sometimes it's very robust and active, and other times, no, it's not. Cancer really changed how I felt about my body. I think we can all agree that it has different effects on everybody. It really changed how I felt about myself and how I felt about expressing intimacy with my husband on physical and emotional levels. From the physical side, between the hot flashes and the dryness and the changes in the shape and size of my breasts and the weight fluctuations and the fatigue and the joint pain. I mean, now tell me how you get turned on with any of those things going on. I struggle with it. And I struggle even to this day with it. There's

sometimes, aside from also being the mother of two young children, that even aside, with all of the cancer things alone, it's tough to really find a way. It's work.

You don't think about your sexual health being work. But at the end of the day, I've started to come to this realization that one of the, I guess, downsides but also upsides to cancer is that it makes you work for yourself in different ways. And sexual health is just one more thing that I think we just have to work on and work through with every ebb and flow that we have. And then the emotional side too, to say nothing of the emotional toll that cancer itself has taken on me, my confidence would wane. I would be adapting to a different looking body and you just feel very... Or I would feel very differently.

But one of the things that I have found throughout all of this and the thing that sort of helped me or really convinced me to do this webinar or to log into this webinar with all of you and to hear what Fran and Sharon have to say and also Sharsheret, was that I really found that communication between myself and my husband. But mostly communication with myself has been paramount. Yes, talking to my husband about how I'm feeling, yeah, of course. And any marriage counselor will tell you of course communication is key. But what I didn't think about was how I talked to myself about my sexual health and how I would bring my husband into that conversation I was having in my head, how I was feeling, how I was thinking, how I was acting on those things and how that may have been leading to different conversations that we would be having.

And our intimacy changed after cancer, but not necessarily in a bad way. We had to learn what really makes us each feel connected to each other, not just attracted to each other. And I think there's a big difference between connection and attraction. There are a lot of similarities, but I think the difference is that when you're connected with the person... Sorry, my daughter has something to say about too. But when you're really connected to someone, it can change the game of the conversation drastically.

So I still struggle with physical intimacy every now and then, especially being the mom of two young babies and being a cancer survivor. And I know that there are resources out there like Sharsheret and others I'm sure that we'll hear about today to help things like specialists and tools and classes and products and toys and all of those things. But I think in those moments when I'm really struggling, I try to remember two quick things, be kind to myself because this is hard work. It's not easy navigating this. And it's also normal navigating this. This is one of the things that we just are dealing with and that's what we do. And then two, to be open, open with myself and open with those around me and with my husband. There's no such thing in my mind as over-communicating. And there's also no such thing as being overdressed or overeducated. So just talk about it, and you'll discover something though. So thank you very much for this opportunity and I'm excited to hear more.

Melissa:

Emily, thank you so much. You had me thinking about things differently. Yes, and somebody just said, they said they love your necklace, and I was like, "I'm going to email her later." I'm not going to say it on the webinar.

Emily:

Cut + Clarity.

Melissa:

But I love your necklace. Maybe you can hold it up before...

Emily:

I can. Yes, I have... Of course, thanks, Kelly, for noticing. I appreciate it. Cut + Clarity. She's a small business out in New York City actually. Some of her proceeds go to breast cancer foundations, so definitely check them out.

Melissa:

And she got a free advertisement.

Emily:

There you go. Yeah, so sorry about that.

Melissa:

No. That's great. That's great. Thank you very much. You know what? We're so grateful that you were willing to share your story and what some people find a very uncomfortable conversation to have. So thank you.

Our first presenter this evening is Fran Baumgarten PhD. She will be discussing how a cancer diagnosis impacts intimate relationships; partners, spouses, maybe as Emily was saying, even the intimate relationship you have with yourself. Dr. Baumgarten is the co-founder and clinical leader of the Center for Cancer Counseling, a two-time survivor of cancer, her passion to help cancer patients and their families manage and survive cancer along with her personal experience with cancer led her to begin this nonprofit organization. In practice as a licensed clinical psychologist for over 35 years, Dr. Baumgarten earned her PhD from California School of Professional Psychology. Dr. Baumgarten, thank you so much and welcome.

Fran Baumgarten:

Thank you for having me. Let me see about sharing my screen here. Hope it works. Okay, good.

Melissa:

It's working.

Fran Baumgarten:

Emily, thank you so much. What a beautiful lead in to my discussion. It was absolutely perfect. And I'll be hitting on some of those very topics from a little bit of my take, so thank you. It was wonderful having you.

Intimacy, as Emily was alluding to, it's not just about sex. It's about this emotional closeness and connection that we feel with people. And it's when we feel safe in being able to share some of our deepest thoughts and emotions and that we feel that we're heard and respected. Cancer, as we all know, challenges these connections. It really throws us into what feels like almost an alternate universe and what I have kind of coined this parallel life that we get challenged with. So you're going along your life and everything's just going along, and then cancer comes and joins you and gets connected to your life. And now you're on these two paths together. And figuring out how to navigate that because the balance goes according to how much the cancer demands.

On the times that the cancer demands a lot, we get to be in our regular lives less, and that balance goes up and down. And this concept came about from my personal experience with cancer and working for 30 years after that with cancer patients and their family members. I was in my 40s when I was diagnosed and had a lot of hormone treatments, a lot of surgeries, a ton of chemotherapy, a stem cell transplant and radiation. And when I got done with that and started working with other cancer patients and their partners, I had to be able to formulate what on earth had just happened and how am I going to put this in a way

where I can manage it, teach people, and then have those conversations really develop so that people's lives can really be fulfilled and gratified.

We all know that it's not easy being a patient. We have to tolerate and endure all kinds of harsh treatments and side effects. And what happens is that really makes us unable and unavailable, both physically and emotionally to participate in many aspects of our life and in many parts of our relationships. And this isolation is really very disruptive to our lives because we watch things happening because sick for so long periods of time. And cancer treatments are a long period of time. And then I'll talk about the recovery in a minute.

It's also not easy being a support person. Seeing the person you love and pain and being overwhelmed emotionally with the same emotions that your partner going through treatment has all the depression and sadness and grief and just worry. But as a partner, as the support person, you almost feel guilty because you're not supposed to... You're not allowed to have these emotions. You're not the one going through these treatments. But on the other hand, you're doing exactly the same road as your partner is doing. And additionally, you're doing this double duty. And maybe you're caregiving for the very first time in your life and you're filling into all the spaces that your partner can't be part of, and that brings along a lot of loneliness and a lot of delayed gratification. When you're in the midst of treatments, everybody's in this waiting for things to be over so life can get back to normal.

There was a gentleman recently that told me that he conceives of his... Him and his wife is the flip side of the coin. They're both going through this experience together. They're a team, yet their experiences are very different from each other. And their tasks are really about having this empathy for the fact that they really don't know what it's like to be in that other person's shoes. But on the other hand, they need to recognize it and they need to be able to acknowledge it so that they each don't feel alone in going through this treatment space.

What I find really could be helpful is really a place of support during treatments of peers and people that know what you're going through. It's much easier to talk to somebody else who's been in your shoes and having your experience, and that really frees up the energy for you to be able to then join your life and not carry all of the cancer emotions with you so that you have time to enjoy your family and to enjoy your partner and to do the things and the very reason for why we're doing these treatments to begin with.

As you move into recovery, I think it's a real shock for most people, realizing that life is really forever changed and the surprise of how long the healing process could take. Most people reference having the flu. You get sick, you get better, you're right back to where you started. There isn't a reset with this. This is really starting anew, and it can be very confusing for everybody around us as we're not kind of in the same place with them. So our partners are usually very relieved, very excited to return to life as normal, expecting us to. And we're kind of lagging behind a little bit because our body just aren't rocking and rolling as quickly as everybody around us would really like us to be able to do. And so we have this time where, "Okay, treatments are over. We're certainly glad that they're over," but we're not feeling that same kind of excitement. We're not really able to connect to our bodies in the way like before we would just be able to reset too.

And when you stop that really frantic activity level, that's when the emotions have a chance to kind of rise up. So people are very surprised by this unexpected depression, anxiety, and grief and irritability. As your body is balancing out from all the chemicals, there tends to be more irritability that happens, plus you're just coming out of months and months and months, and sometimes for a year, of really having to do things that you have no control of. So sometimes it's really hard to tolerate things that aren't exactly the way you'd like them to be. And it's very difficult for people around you to understand because as you start to look better, as you start to look more like yourself, their expectations is that you are more like the person you were before cancer.

I have a very funny story that I'm going to share with all of you. When I was getting discharged from the hospital after my stem cell, my doctor came in to speak to my husband and I about how I did and

everything's fine. And he says, "Oh, and by the way, no sex for 30 days." And I cracked up laughing. I don't think I had laughed the whole 21 days I was in the hospital like this. And I looked at him and I had a great relationship with this man. And I looked at him and I say to him, "Have you really looked at me?" I have no hair anywhere on my body. I have a tube coming out of my chest that's a Hickman because that's the kind of cord I to have with the stem cell and I'm green from being in the hospital for 21 days. I said to him, "Does this really look like a body that somebody's going to want to have sex with?"

And my dear husband turns to me and says, "I'm counting the days and I'm hysterical living." And I say, "Buddy, you better keep counting those days because I don't even know where my arm switches. I mean, I need a minute to breathe here and to just figure out how's this body going to work again. Because right now it's really turned off."

It was interesting that in my process of recovering and as I started talking more about reclaiming your body with people, it was this double-edged sword that we all ended up talking about. You want your partner to want you, to admire you, to desire you, and yet it is this, "How am I going to get my body to start to respond again?"

There was an interesting study that was done with couples that were married over 50 years, and this was the heterosexual study. But in the 30 years I've been practicing, it really pays true even for same sex couples where they asked men, "How did you stay married for 50 years? How did you do it? What are the tricks?" And they all pretty much answered in exactly the same way. They said, "When I look at her, I see the girl that I fell in love with. That's my girl." And it was really interesting to hear them talk about this concept that they had in their mind, that they really never lost that picture.

And when we talk about reclaiming our body, this is one of the tricks we can talk about, this mind-body communication. We know that what we think our body responds with biochemically. If you think about something happy, you're going to feel happy. And being able to reclaim your body, being able to reconnect, it really is about being able to bring up those memories. What did it feel like when your body stirred? What did it feel like when you were excited? And really being able to visualize your body and places where those feelings really felt good.

This is not easy, as Emily was saying. I mean, this is just not an easy task. And Sharon's going to talk about all of the practical things and things that you can do physically to kind of make this also work. But when we talk about mentally and emotionally, this relationship with yourself, as Emily was talking about this ability to self-talk, this ability to do a silent movie and say, "This is the person I love and I want to be with." Couples that have good marriages, this is a good time for those communications also to be able to happen where you identify all the things about the relationship that were good, remembering what it was when you met, what excited you, what things did you like to do together. I mean, this opportunity for growth as a couple is enormous, as well as the opportunity for yourself to run a silent movie and to look at you in that movie and to be able talk to yourself about the things that you really like and appreciate about your life and who you are and being able to visualize it at the same time.

And that self-talk, as Emily was also talking about, is really important, being able to kind of connect and accept your body in the new form that it's in. And also this communication with your partner is just vital because it is that emotional connection. If we kind of circle back to the very first slide, it's being safe. It's that emotional closeness. It's that emotional connection that really allows the more difficult conversations to happen and really allows couples to learn how to accommodate and adjust together both in their lives as well as physically together.

There's just some things in conclusion to think about, and I'm really hoping that these presentations, that the takeaway is really opening up conversations at home, opening up new ways for you to think about things as well as conversations for you to have with your partner. It does take a team to deal with cancer. This is a wonderful opportunity to learn how to identify and talk about feelings, needs and wants. It's an opportunity to grow and learn. I talk a lot about building resilience, not only as a person and as a couple, but as a family and friend.

And if you have children, this experience teaches them. How does a family manage in adverse situations? How do you pull together? How do you take care of yourself? Now, this is the time when we learn how to reconnect and reenter our lives to repair and heal any past wounds to be able to start anew. As a couple, all you need is that desire to really want the relationship to work well. And a trauma like this can highlight that, how important your family is to you, how important your relationship is to you. And so sometimes it can be very motivating to work on really repairing those things in the past that didn't go well, and really together as a team being able to talk about how to move forward in a different, more positive way.

The big trick like Emily is talking about is figuring out how to accept and share your body. And then being able to, in those communications, learn how to make those accommodations and adaptations to the changes that we need. And understanding, of course, that the healing process is both physically and emotionally. But recovery is about moving forward. And I don't know if the time is okay, Melissa, but I would like to say a couple of things about being single.

Melissa:

Yes, please.

Fran Baumgarten:

I think this discussion is very relevant even if you don't have a partner right now. If you look at how we talk about intimacy, those are really nice concepts to have in the forefront of your mind when you're meeting somebody because those are what's important to you. As you're watching the silent movie, if you were watching you and this person, if you were somebody else, would you think, "Oh, that's a great partner for her?" Being able to be mindful and very intentional in the people that we decide to spend time with and having more of those emotional conversations. I think that having cancer really does up our game in so many ways. It really emotionally has us grow in so many ways. And so finding somebody who is sophisticated in that way. And in all my 30 years of working, I have never had a single person, and I've had a lot of them in my practice, somebody and have that person not be just great wanting to be with them physically, having zero problems.

And it's interesting when you think about it because when you're dating, you do want to please the other person. You want them to be happy with you, you want to be happy with them. And so there's a lot of motivation to learn and to listen and to do those accommodations. But here again, we have to be able to be comfortable in our own bodies to be able to even express that or talk about that with somebody else.

So I want to just leave everybody who's single with a lot of positive thoughts on that, as well as the couples that are listening as far as you building your relationships to an even greater height. So thank you. Thank you for having me.

Melissa:

Thank you so much. That was... Oh, can I ask you to unshare?

Fran Baumgarten:

Yes.

Melissa:

There you go. Perfect. Thanks. Thank you so much. That was definitely some thoughts that I know resonated with people, and we're so glad you were able to share. Our next presenter is Sharon Bober, also PhD, who will be speaking about cancer and sexual health. Dr. Bober is an institute psychologist at the Dana-Farber Cancer Institute and an associate professor in the Department of Psychiatry at Harvard

Medical School. At Dana-Farber, Dr. Bober serves as the program psychologist within the Division of Cancer Genetics and Prevention, and she's the founding director of the Dana-Farber Sexual Health Program. As a clinician, scientist, her interests primarily focus on sexual health, cancer risk, cancer survivorship, and quality of life.

Dr. Bober, thank you so much for being here and welcome to the screen.

Sharon Bober:

It's a pleasure to be with all of you. And I'm sorry that was such a long introduction. I was a little bored listening to it myself. So anyway, but I thank you for that kind introduction.

I just want to say that it's really a pleasure to be here, and I really appreciated both what Emily and Fran just shared with all of us. I almost feel like I could just go home now because you've sort of heard it all, so bear with me.

But let me just share my screen. For some reason I'm not... I don't know why... Fran, I know we tried this before. And when I go to share my screen... Oh, there we are. Got it. Okay.

Melissa:

Yeah, perfect.

Sharon Bober:

Good. Great. Thank you. All right, so I'm just going to dive in because I know we have a little bit of time together and I think we're want to leave a time for plenty of Q&A.

So maybe this is obvious, but I'm going to just sort of start by saying, or really give my perspective on just what sexual health is because I think, again, maybe it goes without saying, but maybe it doesn't. Sexual health is really at the intersection of so many different things. It's not just about the physical, it's not just about the emotional, but it really is at the intersection of mind and body and social interpersonal relationships. I will say there's a whole lot of social cultural context that also influences how we feel and think about sexual health. And individually, we all have different goals and values and motivations for why this is important.

So I'm really going to invite you to think with me about sexual health in an integrative way, not as a unidimensional construct, and really appreciating that this is a central aspect of quality of life that really goes across the lifespan. That being said, it is really clear that all of the major treatments that we bring to bear to treat cancer have the potential to disrupt all of those aspects that make up sexual health, right? So when you think about it, that's a lot.

And that may be from the physical point of view, everything from hormonal fluctuations, menopause, body alterations, pain, fatigue, and we'll talk about some of that, to just how we think and feel in all of the psychology that everybody's, just before me spoke about directly, clearly in the context of social interpersonal relationships. This is hard stuff. It's not easy to talk about and the whole communication piece often really needs to get rejiggered a bit. Again, we all have various cultural, religious, social norms that sort of influence where we are. And there are all kinds of assumptions and anticipations that may change on the other side of treatment.

So given all of that, I will say it's interesting that still, and I say still because I've been doing this work for now quite a long time, sexual health is still often the elephant in the room when it comes to treatment, right? The bottom line is, when we do lots of surveys with patients across the country and across the world, this is always one of the top issues that is on people's minds in terms of changes in quality of life. But we also know that providers don't get a lot of training about sexual health. I mean, people essentially go through many years of training and are taught how to assess STIs, STD, how to ask about conception, safety, danger. But in terms of talking about sexual function and sexual health, people really don't get

trained to do that. Patients and doctors, nurses are often unsure about who's supposed to start that conversation. So often, that is kind of a funny thing where nobody wants to embarrass or put off the other person so it doesn't come up.

And I would say that crazy as it is given that we live in a culture saturated with sex and graphic sexual images, we actually have very little conversation about real sex and real people and real problems. So it's still kind of taboo in that way. And the bottom line is that for most people who go through cancer treatment, if you hear something, it's typically not sufficient. It's typically incomplete. So it's like you get a little piece of the puzzle, but you don't get the whole puzzle.

So in terms of when I'm thinking about why this is important, I really just want to sort of put a plug in for the fact that when sexual health is going well and it is satisfying, it's actually also good for health and wellbeing, right? Beyond the fact that it boosts mood and can relieve stress and allow people to feel more intimate and connected, it actually is good for everything from heart health to pain relief and immune function. So lots of good reasons why we need to think about it.

But I also really want to underscore the point that none of the symptoms that are most prevalent, those symptoms typically do not get better by themselves, right? They typically do not self resolve. And in contrast to lots of other side effects of our cancer treatment, which typically get better over time, sexual function typically does not improve by itself.

So the framework that we bring to this, certainly our work at the Dana-Farber, and I think broadly lots of people use this biosocial framework, really again just understanding that we are looking at how all of these pieces go together. We help people figure out where there are problems, create an action plan, a roadmap for what to do, and really thinking about that in an integrative way, not as a sort of a single concept.

So that being said, that's the prologue, I appreciate that I think I was largely brought here in some part today to talk more about, as we said, sort of the functional stuff, what do we need to know about getting things back on track. I want to talk in great detail about vaginal health and menopause because I think, again, this is something that we all sort of, or many of us, go through one way or another whether it's treatment-induced, whether it's having menopausal symptoms intensified by treatment. But honestly, most women get only a little bit of the whole picture and don't get all the information they need.

So when it comes to menopause broadly... That's a busy slide, I'm going to go back for a second. I just want to say when we think about menopause broadly, we sort of can think of all of the symptoms of menopause. And menopause really is when we're talking about ovarian function turned off. Whether we turn it off or whether it gets turned off naturally, the ovaries are no longer producing estrogen. The symptoms of menopause are really categorized into two big buckets. They're the vasomotor symptoms, so that's like hot flashes and night flushes and a lot of the thermoregulation issues. Not going to talk about that today. The other big bucket are what we call the genito-urinary symptoms of menopause. So again, the symptoms of menopause related to genital tissue, vaginal health, and urinary tract, okay?

So very specifically when we think about GSM, the genito-urinary symptoms of menopause, we're talking about what happens when we have a significant loss of estrogen in the vagina, the vulva, and the urinary tract. So in terms of vaginal changes, what does this mean? Very concretely, we lose blood flow, we lose lubrication, we lose stretch or elasticity to that tissue. Together, that means that we can have more irritation, itching, burning pain with or without sexual activity. The vaginal pH changes. So we may be more prone to infection.

In terms of the external tissue, the vulva, the tissue around the opening of the vagina, we lose collagen. That tissue gets thinner and it is prone to... It's fragile, it's prone to tearing. We can have some bleeding, right? So we also lose about half of our testosterone. Our adrenal glands make about half, but our ovaries make about half our testosterone. And there are also potentially urinary symptoms. Again, not going to talk a lot about that today, but just will notice that millions of estrogen receptors in our lower urinary tract when we lose estrogen, it is also not uncommon. The women just notice changes around peeing, right?

More frequency, more urgency, maybe vulnerable to UTIs. These are a cluster of symptoms called GSM, which people really need to be aware of in terms of how to manage.

I say this because, again, I'm going to go back and say this clearly, this is clearly related to sexual health and sexual function, but it's also clearly related to just health and wellbeing in terms of vaginal health. If you want to get a GYN exam comfortably, if you want to go to the bathroom and pee and wipe without pain, you need to make sure that that tissue has moisture, right? So this is again related to sexual health, but I want to be clear, it's not only about sexual health.

So from our perspective, when we're thinking about managing these side effects, very concretely, we think about what women need to restore vaginal health. We need to replace moisture, we need to replace stretcher elasticity, and we need to get blood flow to that tissue in order to keep that vaginal genital tissue healthy. So very specifically in terms of restoring moisture and managing dryness, I just want to say this is not complicated, but it is definitely information that most women often do get. What people hear if you have dryness is use a lubricant. I want to be very clear that a lubricant, and we'll talk about that, is helpful to reduce friction for sexual activity, but it does not hold water in the tissue. So I'm not going to ask how many folks on this call put moisturizer on their face before they go to bed at night. But I will just say, if you're moisturizing your face before you go to bed at night, you should probably be moisturizing your vagina. Meaning that there are vaginal moisturizers. These are products that are specifically formulated to hold moisture in that genital tissue.

So for any woman who has loss of estrogen, again, treatment-induced menopause, menopausal symptoms that are intensified, just plain old menopause, really important to keep that tissue healthy partly by using regular, having a regular moisturizing regimen. So there are roughly two broad categories of vaginal moisturizers. There are over the counter. You do not need a prescription, over the counter moisturizers. There are a variety of different types of moisturizers, but typically people need to moisturize three to four times a week. Like anything else, you can have more dryness or less dryness. So that's an individual kind of concern that you have to figure out what works for you.

I will just say if you're using a panty liner, this is a little thing that often we don't think a lot about. Panty liners wick away moisture. That's an issue if you have vaginal dryness, right? You also have to make sure that we're moisturizing internally and externally. So not just inside the vagina, but in what we call the introitus, the tissue around the opening of the vagina gets dry. You need to make sure that we put moisturizer there. You can use also something like pure coconut oil, right? But the point is that you need to moisturize that tissue. And you need to do that as part of self-care, right? That just becomes part of your regimen of self-care, kind of like brushing your teeth or taking a shower or anything else you do on a regular basis in an ongoing sort of way. And I would say again, that's related to promoting sexual health, but not only because of sexual health or whether you are or not sexually active.

Other broad category of vaginal moisturizers are by prescription. Typically, they are using low dose vaginal estrogen, local estrogen, not systemically absorbed, not hormone replacement therapy or something called vaginal DHEA. It's a precursor to estrogen. So I recognize that this is a little more complicated. There are a number of now large cohort retrospective cohort studies looking at women after breast cancer, looking at women who've used vaginal estrogen compared to those who have not. In the large cohort studies that we have, there is no increase in recurrence. So we have greater... I would say we have a growing database of evidence that vaginal estrogen is safe after breast cancer. But again, this is an individual question. It's something you just speak with your oncology team about, not making any large declarations, but just to say this is often an option, especially if over the counter moisturizers are not adequate. Something you can talk with your team about.

So bottom line is, if you have dryness, you need to moisturize that tissue and it is not going to cut it with a lubricant. You need something that is specifically formulated for the tissue to moisturize.

That said, lubricants can also be helpful with sexual activity, solo sex or with a partner. I'll just say a couple of things about lubricants in general. Stick with something water-based or silicone-based or a

hybrid. I would recommend staying away from glycerin-based products. Glycerin can act like a sugar and promote a yeast infection if you're vulnerable to that. Again, try to stick with lubricants that are perfume-free and don't have a lot of junk in them. And I would say lastly, lots of lubricants on the market now that are sort of promoted to be sort of warming or to enhance sensation, but especially if you're someone who has more fragile sensitive tissue, those warming loops can often be pretty irritating or painful so I would stay away from those.

Okay, so going to switch gears to say that in addition to all the moisture stuff, and if anybody hears anything, often it's about dryness, after cancer in general, it is very common that women quickly have some pelvic floor dysfunction, that there are changes in pelvic floor health. Bottom line is in terms of the pelvic floor, we have a sling of muscles that go from front to back, tailbone to pubic bone. They're really at the base of our core muscles. And those pelvic floor muscles post menopause or post estrogen loss can often become two tensed often without our awareness. But those sort of hypertonic or over tensed pelvic floor muscles can be directly related to why sex hurts. So the bottom line is that we have to learn to relax those pelvic floor muscles. That's actually key for pain-free sex, for getting a GYN exam, for being able to have an orgasm.

I'm going to mention this because this is not an uncommon symptom or a cycle that happens on the other side of cancer. If you look at that top wedge where we talk anticipating pain, there's a name for this, we call it vaginismus. But the bottom line is that if you have ever had any kind of penetrative activity or intercourse and it hurts, our bodies kind of go into alert mode, right? That there's something that we need to be reacting to because it's painful. And when we do that, not just happening up here, our pelvic floor muscles tense up. Most of us know exactly what that feels like when you sort of clench up or tense up in anticipation of pain. So the body braces literally at the pelvic floor level. And paradoxically, when you brace, when you tense up, guess what? It makes sex hurt more because those muscles sort of bear down and the vagina closes in, right?

When we try to do that, and we do that more than once, we sort reinforce a very strong connection, mind and body, that sex is painful. And we have to sort avoid that because we're sort of anticipating that it's going to be worse the next time. And that's sort of a very common cycle. I say that because, well, first of all, you could use all the moisturizers in the world, all the lubricant in the world, if you're having pelvic floor tension, if those pelvic floor muscles are overly tensed, then the bottom line is that it's not going to matter what else you do. We have to also attend to that pelvic floor.

So lots of options for rehab and recovery in terms of the pelvic floor. In terms of our program, we work very closely with pelvic floor physical therapy. There are a number of very good strategies for helping people relax the pelvic floor, how to learn how to flexibly become aware of what's happening in the pelvic floor. I gave you a little example of those sort of colored silicone dilators. Those are literally sort of static cylinders which women can use for themselves to begin to stretch that tissue to gain more capacity, to be able to have intercourse comfortably and to learn how to relax the pelvic floor while you're doing some gentle stretching.

So I will also say I'm a huge fan of vibrators. Vibration therapy is actually besides feeling good hopefully. Really, really healthy for that vaginal tissue. We often think about vibrators just from the point of view of pleasure and sex toys, and that's true and it's awesome. But it's also really helpful to get good oxygenated blood flow to that genital tissue to basically relax the pelvic floor, enhance circulation, and decreased pain. So part of I would say general health and wellbeing and recovery on the other side of cancer for lots of women is figuring out not just what feels good, but how to get that tissue healthier. And vibration therapy is certainly one of the things that we know is very useful.

So I only have a few more minutes, but I just want to say that I'm very aware that when we think about all of the kind of stuff I just talked about and all of the stuff you heard previously from Emily and Fran, it is not a coincidence that often women talk about low desire, right? First of all, low desire is the number one problem that women talk about on the other side of cancer, that we just don't have spontaneous desire.

And all of these things are, from my point of view, kind of ingredients and a recipe that sort of contribute to that. And I really just want to make a couple of very important points. One, we know that sex should not hurt. If it hurts, you're not going to have desire. And if you don't address that, nothing else is going to matter, right? That's really important.

Two, we know that after cancer, desire often becomes less spontaneous. It is not automatic. Desire is not like a light switch where you have it or you don't. So I say that because every film, TV show, romantic book we read or look at or hear on tape, it is automatic. It's completely immediate. It's like a spark. It's like when you're first dating, it's like when you're on your honeymoon. It's like when you're on vacation and everything is perfect and the stars align. That is not real life. For real life, for real women, especially at midlife after cancer, et cetera, it's not spontaneous, right? So what does that mean? We need to switch our thinking about desire and understand that desires and experience, we have to support and cultivate, rather than expect it just to be online. So what that means very concretely is that when we think of desire from the point of view of being responsive, meaning that desire is something that you happen in response to being aroused, in response to intimacy, in response to a pleasurable experience rather than a starting point.

I have a colleague who loves to talk about the lava cake. So I'll use her metaphor, although I have a different metaphor that I like, which is to say, how many of us have dinner, feel totally comfortable or not hungry? And then all of a sudden you see somebody come along in the dessert cart and there's the most delicious, smelling, wafting, oozing chocolate lava cake, and you think, "Oh, actually I think I had a taste of that," because it just sort of gets you primed and all of a sudden you're perfectly hungry. So I would just say the metaphor I often use, this is more about exercise, which is just to say that when my alarm goes off at 5:30 or six o'clock in the morning in Boston when it's snowing and cold in the wintertime, I'm really not motivated to go to the gym. But when I start to move, I feel better, right? And so it's by actually doing something, I jumpstart a feeling in which I'm actually more motivated to keep going. I think you get the idea.

I will just say, when we think about desire in that way, if you're feeling pressured, if you're feeling guilty, it's not going to work, right? It has to be something that you do out of choice. But we do need to think about replacing spontaneity with that notion of anticipation, with planning, with actually the primacy of doing something. And that may very well be creating some new scripts, some new habits because what we used to do may not be working.

So I'm going to sort of wrap up because I know I've talked probably for too long, but I really want to clarify, although I'm not going to talk about any of this today, we really work with sexual health at the intersection of all of these things. So although what I spoke with you about I think is really important starting point, again, really appreciating what Fran and Emily talked about, I think we really need to think about all of the other pieces, the thoughts, the feelings, the body awareness and compassion, the anxiety avoidance piece that often comes into play and just what we need to do in relationships or certainly thinking about the interpersonal piece that we may need to be creative about or broaden our repertoire or think more broadly about doing something different in order to move forward in recovery.

So I'm not going to share the rest of those slides with you today. I don't want to take up the rest of the time. But I will just say this, and I agree with what, again, both Fran and Emily said, I think that partners have no clue about how to deal with this. I think they have no idea. No one talks to them about that. So that people often need some support, and I think it's really important. My last piece here is that you can't think about sex as a military campaign, right? It's got to be really sort of pleasure-focused so that if we can really sort of take off the pressure of making this super goal-oriented and really sort of broaden our focus on pleasure and sensuality as a starting point, it's very freeing. But partners need to understand that, and that has to be something that gets communicated together.

So in summary, this is really time for a new chapter. I would really argue that nothing is the same. We cannot go back and do what we used to do and expect it to be the same. We really have to think about

being creative here, but recognizing that you're going to have to take your time, work at your own pace and really have an action plan for what to do because this does not take care of itself. So that being said, I'm really happy to help with questions or talk with the group as we go. And thank you for having me today.

Melissa:

Thank you so much. That was a lot of information, a lot of really good information. We could have listened to both of you for an hour each. We do have some questions that came in tonight and also many that came in during the registration process.

Again, you still have the opportunity to ask questions in the chat box. Or if you'd like it to be anonymous, send those questions directly to the account listed as just Sharsheret. Just Sharsheret. And then nobody will know.

I will say that both Fran and Sharon have been generous and said that if we go over for a few minutes with questions, we can do that. But let's see how far we get.

The other thing I want to say is we've combined a lot of questions that were similar. So listen for overall content and not the exact wording of the question you asked. Okay. Here's something that we didn't get to discuss by either one of you, but somebody asked, "How can cancer patients ensure that they're practicing safe sex, especially if their immune system is compromised?"

Sharon Bober:

I'm happy to take that if you want me to, Melissa, if that's fine.

Melissa:

[inaudible 00:50:00].

Sharon Bober:

Okay, it's fine. So I would just say, that, I think again, is on a continuum, right? So it's one thing to say that you're a little bit immune compromised versus you are neutropenic, right? So it is definitely on a continuum. I think that there are for sure pretty clear guidelines if you have an extremely low white count, if your doctor is concerned about you being able to be out in public or to be able to go to a restaurant or go out to eat at all, it would really just make sense that when it comes to any kind of sexual activity, one, first and foremost, you have to make sure your partner's not sick, that you're both healthy.

But the bottom line is that in general, if you are living with your partner and you are sharing all kinds of close in terms of lots of other ways, sex by itself is not something that's going to be more compromising. Does that make sense? So I would just say in general, if you're unwell and your partner's unwell, it doesn't make sense to be sexually active. But if you're talking about an immune system, that may be somewhat compromised. But again, in terms of day-to-day, you're living with your partner and you're sharing meals and you're sharing a bathroom and you're practicing good hygiene, there's nothing by itself that would mean that sex would not be safe. Does that answer the question?

Melissa:

That sounds like a great answer. Thank you.

Sharon Bober:

Okay.

Fran Baumgarten:

I'd like to add something to that too.

Melissa:

Please.

Fran Baumgarten:

Because sex doesn't necessarily have to mean penetration. There's lots of ways to have sex and have an orgasm. And so I think sometimes that couples don't always think about that especially during treatment when you're not as really able to even have penetration as easily. So I think just kind of recognizing that, that being able to touch each other and have orgasms, you don't need to have penetration to have that happen.

Melissa:

Yeah, that's a really good point. Thank you. So another question we got, which was answered but led to several follow-up questions. Somebody asked, "What do you recommend for vaginal health during and post-treatment?" So you did talk about moisturizing is self-care. And several questions came in tonight. Can you recommend some brands of OTC moisturizers?

Sharon Bober:

Absolutely. So I'm very conscientious about not trying to necessarily recommend products per se, but I will say this, there are a number of moisturizers on the market now that are hyaluronic acid-based products. Dermatology companies have used hyaluronic-based products for many years. Hyaluronic acid is a molecule that holds water. Several companies now have sort of harnessed that technology to vaginal moisturizers. So Good Clean Love makes a very nice product. There is something called HYALO GYN. There's something called Gynatrof. So I would say that any hyaluronic-based vaginal moisturizer is probably the most effective over the counter moisturizer. And moisturizers, just to be clear, typically come in a couple of different delivery systems. So you can get something that is more of a cream or like a gel-base that comes in an applicator, or you can get something that is typically more of a suppository that you insert.

I will say that if you use... Again, remember, you need to moisturize internally and you need to moisturize around the opening of the vagina. So if you get something that is like a suppository that you insert, you may need to use something additional, like let's say coconut oil, and I mean like pure coconut oil, around the external, outside vulva, opening of the vagina, in order to keep that tissue supple. So inside and outside. You don't need to cover the whole vulva, but around the opening of the vagina.

Melissa:

That's helpful. Thank you. Okay, so we got two questions that were the opposite side of the same question. So someone asked about encouraging a partner to touch them because they're scared of everything that you've been through and they don't want to hurt. And then somebody else asked, "When my libido is low and my partner has a higher or stronger drive, how do you manage that?" So maybe Fran, can you give that a go and then Sharon, if you have anything to answer?

Fran Baumgarten:

Yeah, I mean it's very tricky because it's very personal as far as really engaging your body, having your partner. It goes to that intimate connection and feeling really safe. And being able yourself to be able to touch yourself and get comfortable I think is really important, especially when you've had mastectomies

and reconstruction and just really getting a feel for yourself in that way. This imbalance in sexual desire and libido is always a real struggle, and it's also personal how couples work it out. Sometimes one couple will just pleasure the other person. It doesn't always have to be that it's definitely a joint activity together where both of you are sexual together. And being able to give and take in that way in a relationship, I think is pretty common for a lot of couples to have.

Sharon Bober:

Yep, I absolutely agree. Sorry. See, I'm terrible at multitasking. I was trying to answer the chat box about the same time.

Yeah, no, I completely agree with what Fran said. I guess I would just add to that, and I would say that I think it's super important and helpful to remember that, especially in the context of everything we're talking about, desire is not going to be spontaneous. I just feel like that is something that we are all sort of under this cultural miasma of misinformation, that desire is supposed to be spontaneous. And if you don't have it, it's a problem.

The issue is more like when we plan for something, when we anticipate something, you have to cultivate an experience that feels good, that's going to feel intimate or connected or pleasurable in some way. Maybe not pressured, maybe not about intercourse, maybe not about penetration, but you have to do something in order to jumpstart a feeling that may allow you to feel kind of motivated to keep going. Does that make sense? It's a very different perspective. So when people say, "I don't have any desire and my partner doesn't have any desire, what do I do?" The assumption is like, there's nothing to do because you don't have any desire. And from my point of view, that's awesome. That's the starting point.

So the question is, "Okay, you don't have any desire, but now what?" What can we do to figure out what might just allow you to feel connected? What might feel sensual? What might allow you to have an experience in your body by yourself or with your partner that doesn't feel scary, that feels like something erotic in some way, that is you're willing to explore without pressure, again, of it having to lead to something?

That's a game changer. If from a communication point of view, couples may decide, "We're going to just take intercourse off the table. That's just not where we're going with this," that is incredibly freeing, right? Because then there's lots of room to explore without pressure and to then sort of see what may sort of jumpstart some feeling.

Melissa:

Thank you. I'm going to ask three more questions, but very quickly I see something popped up. We were talking about moisturizers. Somebody asked if using Vaseline is okay. Can you please-

Sharon Bober:

I don't. Please, please, please don't use Vaseline. Vaseline is a petroleum-based product. It does not allow this tissue, the skin to breathe. I do not. I mean, put it this way, women have used all kinds of things in the face of nothing at all, but given the option of other products, even something like coconut oil, I would prefer that to any kind of petroleum-based product because it really does not allow the tissue to breathe.

Melissa:

Okay, thank you. All right, how about somebody who's dating? So this is someone who's dating post-cancer treatment, during cancer treatment. How is it? And let's assume it's not long-term relationships. How can they get beyond this? How can they start to broach this topic even? It's a different place than with somebody who's been with somebody for many years.

Fran Baumgarten:

Well, I mean, I'll start out and then maybe chip in Sharon here. I think it really has... You have to get comfortable with yourself having had cancer and the treatments. I think that's where you have to start because these are important conversations to have early on. I mean, if you're just casually dating and just going out on a couple dates and just having fun, you don't think it's going to go anywhere, maybe you don't have to have those conversations. But it's really important to be comfortable enough to be able to talk about this I think early on in the relationship to know if you even want to bother with this other person. Because otherwise you're wasting your time if you start to have feelings for them and they're not mature enough or able to meet you where you're at.

And I think what's really interesting in my talking to a lot of people that are single is that almost every time that they tell somebody, that person knows somebody that's had cancer. It's not this odd experience anymore. And so people don't tend to be as afraid of it as I think maybe they did 10 or 20 years ago. It's much more accepting, it's less scary. You don't seem to run in as many problems with people rejecting you or not wanting to be with you. That from all the people that I'm talking to, they're single, that's very, very rare that that ever happens.

Melissa:

Yeah. You mentioned something similar to that in there. Yeah.

Fran Baumgarten:

Yeah.

Sharon Bober:

I have a couple of other thoughts on that, if that's okay. I would say this, I think in general... Well, I would say a couple of things. One quickly, I think it's really important to have a kind of clear canned language in your head about what you're going to say when this comes up, because I think the idea of not knowing how to start to disclose this, you're not going to make that up when you're sitting there in Starbucks, right?

Melissa:

Yeah.

Sharon Bober:

And the thing that I always recommend really is that people have sort of three major categories for how you do it. You can have a very brief giveaway line at the very beginning if someone says, "Oh, what are you up to? How are you? That It's like, "Well, it's been a complicated year. I had some health issues. Really don't feel like talking about it." But just something that's like a little bit, and see how the date goes, right? And if you like this person, you go out again, whatever, then you can share more.

So category two is like, "I had breast cancer. Not sure I want to talk a lot about the detail, but it wasn't an easy process or whatever." And I would say at that point, see what you get back. Just stop talking and see what the other person says. And if they seem to be like, "Oh my goodness, tell me more, how are you?" That's fine. If they're the kind of person who looks like they want to run out the door, good news, you don't want to be with that person. Now you know. You can leave. So you don't want to be with somebody who's not going to be able to handle that.

And then I think the third category is as you get to know someone, and if you like them, you can certainly share a lot more, right? But the bottom line is, and I would say this, none of us are defined by our body parts. None of us are defined by any one aspect of our body. I know that's something people often worry a

lot about, "How will a partner think of me if I don't have boobs, if I have reconstruction, if I only have one?" All of that. And I would just say that, in the same way that none of us think about being attracted to somebody because of a body part, people are not going to be attracted to you in that way. They're attracted to you as a whole person, right? All of you is what makes you attracted to someone.

And I just think it's important in terms of dating to recognize that it's a process of disclosure. It's not all or nothing. And there really isn't a right or wrong way to do that. But that I think it's really helpful just to have some canned language ahead of time in your head so that you don't have to feel like you're making it up on the spot.

Melissa:

Great advice. Thank you both. Okay, I think this one's for Dr. Bober. "Can you talk about any homeopathic hormonal support? Any advice on something called seed cycling?"

Sharon Bober:

No.

Melissa:

Okay.

Sharon Bober:

There's really no evidence for that. Homeopathy is complicated in terms of... I know people have strong feelings about it, but I would say from a evidence-based perspective where I sit, we really don't have any... There's not really much I can say to add to that.

Melissa:

Okay. I just want to note that we talked a little bit, I asked a question about someone who's a... "How can I tell my partner it's okay to physically engage, that you're not going to hurt me, things like that?" So somebody actually reframes it in a different way, asking, "How to talk to my partner and let them know I don't want to be treated like a patient anymore?" And one of the things we didn't talk a whole lot about tonight was that change in going from partners to caregiver patient and how that impacts a relationship. Fran, do you want to talk for just a second about that?

Fran Baumgarten:

A second? Really?

Melissa:

I know it's unfair to ask of you, but...

Fran Baumgarten:

Right. Right. Right. Yeah. Well, I mean of course, this is the double-edged sword. I think we never want our partners to just look at us as patients. And so during that whole treatment phase when we really are patients, I think that's the time that it's really important to be able to gather whatever times you can together to keep the relationship connected, to have those times of spending, even if it's watching a movie or if it's taking walks, it's capturing that. And like I spoke about, it's how do you stay in your life and not just have the cancer dictate everything that's going on with you? It's really a balancing and it's really a trick.

And I think, like I said, I think the most difficult part becomes in that recovery when you're not really recovered, you're just kind of in recovery and you're still not quite yourself, but yet you know everybody is looking at you as if you're just back to normal. I think it's just a struggle that if you can keep the connection, if you can keep yourself as a couple doing things together so you don't forget what that's like, that's the important part.

Melissa:

Thank you. Thank you.

Sharon Bober:

I just want to also say that sometimes partners have no idea. I hear that a lot. Somebody will say to me, "I'd really like my partner just to throw me on the bed. That would be really sexy because actually treating me like a patient, I'm kind of done with that." But partners have no clue. So being able to, I think, give partners permission. And I know that's complicated because some days you might be in the mood for that and some days that would be the last thing you'd ever want. So again, to I think Emily's point at the very beginning, it's interesting that we end on that same note. You have to communicate, right? I mean the thing that you have to do maybe differently if you didn't have to communicate a lot before is maybe you need to communicate a lot more now. But being able to also ask for what may be kind of a little exciting or a little crazy sounding or something that may be different than your usual habit is important.

Can I actually speak to a comment somebody asked about the vaginal laser?

Melissa:

Yes.

Sharon Bober:

I see that. And I really want to talk about that for one quick second. So vaginal laser is something that is marketed a lot. We've talked a lot. There are plenty of folks who have laser CO2, laser Mona Lisa, talk about the idea that you can sort of vagile the inside of the vagina and it sort of forces the body to sort of reoxygenate and refortify that tissue on its own. I will just say that the only really good quality large randomized control trial comparing laser to sham, which was published a little less than two years ago now, showed no difference between laser and sham laser.

So the reality is that it may not work for women who in particular have more sensitive tissue, who on an aromatase inhibitor who are on Tamoxifen, laser may actually end up being not helpful at all or may actually be painful. So I would just say that we do not have good evidence to recommend vaginal laser for vaginal atrophy post breast cancer. It doesn't mean that people can't try it. It is not paid for by insurance. People have to pay out of pocket. Sham just means somebody just asked that when you compare, it's the control group, right? When you compare real laser to what people think is laser, but it's actually not anything. When you compare the two control to intervention, there was no difference.

So I would just say that we cannot recommend laser as being an evidence-based intervention. And that again, you have to be careful, especially I would say if you are on any kind of aromatase inhibitor or estrogen suppression.

Melissa:

Thank you so much. I wish we could spend much more time. And we'll have another webinar on this topic sometime. But for now, I want to thank both of you so much for sharing what's your passion, sharing your expertise. And I want to thank Emily for being so open and sharing her story. Of course, I

want to thank Daiichi Sankyo, Pfizer, and the Centers for Disease Control and Prevention for their support.

Again, I wish we had more time together, but I do want to point out that Sharsheret has some additional resources, additional information on these topics. When you fill out the evaluation, and I saw that the link was put in the chat box twice already, maybe we can put it in one more time, you can click that and still listen to the end of the webinar. When you fill out the evaluation, there will be an opportunity to order these free resources by mail or as a digital download. Please be on the lookout for that request opportunity when you fill it out.

Finally, I want to remind you that Sharsheret is here for you. Our social workers are available to answer questions, provide support, and connect you to resources. Tonight's topics were difficult ones, emotional ones. Please don't hesitate to connect. You can reach our social workers through the email address in the chat box now, which is just clinicalstaff@sharsheret.org. There's going to also be an opportunity in the evaluation for you to request one of our social workers to reach out to you.

Thank you, Deborah, for putting that in. Let's just finish with that survey link one more time. Thank you again to all of our speakers. We're very grateful. And have a lovely evening. Goodnight.