



**BREAST CANCER NETWORK OF STRENGTH
ShareRing Network
Wednesday, June 18, 2008
"Maintaining and Regaining Intimacy"**

ARLINE KALLICK: Welcome everyone to the ShareRing Network Teleconference this evening. And again I will remind everybody that, as you probably most of you know, Y-ME National Breast Cancer Organization is now the Breast Cancer Network of Strength. Our call will begin with tonight's speaker, Emily Harrell. Emily is the licensed professional counselor and sex therapist, and she began her professional career at the University of Georgia where she received a Bachelor of Science in Psychology and a Bachelor of Arts in Sociology. Following her undergraduate work Emily moved to Chicago to pursue a Masters of Science in Marital and Family Therapy at Northwestern University. She stayed in Chicago and continued her training with well-known sex therapist Dr. Laura Berman. Currently she also works at the Berman Center, providing therapy and psycho education to couples and individuals using the Mind-Body Perspective to help clients repair and enhance intimacy and sexual functions.

Our topic tonight is "Maintaining and Regaining Intimacy". Following Emily's presentation there will be a question and answer session, and we will end with small group discussions. We realize it's difficult to answer everyone's question in a one-hour teleconference, so if your question does not get presented during the question and answer or the group discussion please call the Breast Cancer Network of Strength. Our hotline number is (800) 221-2141. The hotline is answered by certified peer counselors who are breast cancer survivors, and it is available to you 24/7. When presenting a question to Emily please be



courteous to other callers by keeping your question brief and realizing this isn't a private consultation. A transcript of each call will be available at our website one week following the call, so visit our website at www.networkofstrength.org. Also podcast recordings will be available online at networkofstrength.org/podcast. And there is a link to podcast page from the ShareRing page. And that would be at networkofstrength.org/ShareRing.

We're very happy to have Emily Harrell with us this evening, and we will now begin our program.

EMILY HARRELL: Thank you for everyone for being here. Let me start by just saying that I recognize that every woman's experience with breast cancer is different, and your ability to manage diagnosis and treatment commonly changes over the course of the illness depending on medical, psychological, and social factors. So keep in mind that when I'm speaking that some of the concerns or issues I discuss may not reflect your experience, but I will try to highlight the concerns that I feel are most common and the ones that I see most frequently at our office.

The topic itself of sexual function and intimacy is one that is often overlooked when people talk about cancer. Most people think that the cancer will just affect their breast, but by now you mostly know that probably, how far from the truth that is. Even the medical field is programmed to focus on our physical health, and they often have received little education regarding sexual impact and how to address them. Sexuality and intimacy are very complex and multifaceted. Sexual function can include issues that are medical, emotional, and



relational. Most of the time it includes all three since these areas overlap in several places. So I'm going to try and address all of these areas and explain some of the connections to you tonight.

I think we should start by just focusing on the physical. I do want to remind everybody before I start this section that I'm not a medical doctor, and that even though I feel it's important to discuss the medical treatments and options today in regard to sexual function, I encourage all of you to make these decisions with the support of your oncologist or the doctors that you are working with. I do want to address them, however, because I think they so frequently get un-addressed or questions don't get asked to the doctors, and sometimes doctors don't have the answers.

To begin the obvious physical changes are usually involving the breast. And you know, as you know there are several procedures to remove the breast cancer so there are a variety of possibilities of the type of change you may have experienced or currently are experiencing. Some of you may have had a lumpectomy on one breast, others may have had a double mastectomy, some may have opted for reconstruction, and others may have not. Either way, the breast is a prominent, personal, and social sign of femininity that can be very difficult to lose or feel is negatively altered. Some of you will also lose your hair or have lost your hair. Even though that's temporary, we know how difficult this period of time can be. Body image is something that many women struggle with before they begin the process of breast cancer, and often have not been given tools to focus on healing.



One of the things that we talk about here when we get someone who has breast cancer, and sometimes people who don't, is really preparing yourself and your partner for the changes your body may go through. Some people find it helpful, and others don't, to look at pictures of what your breast may look like after a lumpectomy or a mastectomy, and sometimes even sharing that with your partner. It can, you know a lot of women have said to me in my office they really, that moment that they first revealed their breast to their husband or their partner was one that they will always keep in their mind. And sometimes the partner's really shocked by what they see because they really had no idea what to anticipate or expect. Something to alleviate that first initial shock and can be helpful with that is sometimes preparing for what it may look like.

Another thing after you've gone through the process of change is something we recommend doing here may sound counter-intuitive to some of you is standing in front of the mirror and trying to learn to accept your body just the way that it is, focusing on the things that you love about yourself. Even if you struggle, even if it's something really small like, you know, the curvature of your shoulder or just the way that your eyes are shaped, really trying to emphasize those beautiful things that you really embrace about yourself physically. You know maybe even hopping out of the shower and rubbing lotion on your body very gently and really trying to appreciate all the things that our body does for us, and all the different purposes that it serves. And for the parts that we struggle with, whether that be your breast or a part you struggled with before, we try and talk about coming up with a positive refrain. I had a woman and she was talking about how she really just couldn't come up with a positive refrain for her stomach. It was something that really bothered her. She had all these stretch



marks from having her children, and she just felt like it was something she was so ashamed of. After a little bit of work and a little bit of struggle, she finally came up with the frame of calling it her love map, of calling her stretch marks her love maps because they led her to so much love. This is just a simple example, and everyone is different and unique in what they come up with, but I challenge you to be creative because this is something that is very difficult.

It's also really important to talk to your partner about the struggle you're having with your body image and the things you're feeling. As you go through them, the fears that you have that maybe your partner won't find you as attractive anymore or, that there's certain parts of your body that your partner is disturbed by or grossed out by. I've heard all sorts of language. So you know, making sure that you talk through those fears with your partner. A lot of times we assume too much; we project onto our partners all the things that we think about ourselves or the dialogues we're having with ourselves at our worse moments. And sometimes our partner, if we give them the opportunity, is thinking actually a really beautiful thought or a wonderful thought. When you're trying to be intimate and you're first beginning the process of attempting to get close again, this can be really difficult. You know no longer, maybe, can your partner hold onto your breast the way that he used to or caress them, or maybe that was an area of great sensation for you or pleasure.

One of the things we talk about to make you more comfortable might be, you know, using appropriate lighting, maybe candle lighting, wearing lingerie to help you feel more comfortable when you start to be intimate again. There's nothing wrong with this process.



Getting comfortable is something both of you are going to be doing together. Some couples even find it helpful to laugh about it, to talk about it, to talk about how, you know, this can be difficult, and some couples can really join on how this is a loss for both of them. I've heard of couples even having their last boob hurrah, you know. If the woman's going in for her mastectomy and maybe they have sex one last time and really enjoy and embrace that breast and say goodbye. You know that doesn't fit for everyone, but you have to find your path and your journey together.

Some of the less obvious symptoms that get brought up because they're not physical in that we can see them that I hear a lot are vaginal dryness. This is a huge one that can interfere with sexual function and sexual pleasure for both you and your partner. This can be caused because of the, you know, immediate menopause that many women get put into, and the lack of estrogen. It can also be a result of the chemotherapy.

So one of the things we start out with is, you know, first course of action being just lubricants; talking to your partner about going and maybe exploring with some different kinds of lubricants, seeing which ones are a best fit for you. Some people may prefer one that's thicker, one that's a little bit more liquidy or slippery. It really just depends, so you know some of the ones that I recommend here we start out with is Replens, which is a vaginal moisturizer; it's not actually a lubricant, that you use right before sex. You actually use it when you're not having sex regularly. And that just helps re-moisturize the vagina, just like you would moisturize your face. And you know our vagina needs moisture. So you know more of the ones that I recommend for right before intercourse would be Firefly, which is one



that has a lot of shea butter. A lot of women that are going through menopause really love this one because it's thicker. And it does have a little bit of an odor, I'll let you know, that some people find unappealing, but other than that this can be a really good one. It also has a lot of really natural ingredients, not a lot of chemicals, so that can be really preferable, especially if there's a tendency for irritations. Another one's called Pink, and it's got vitamin E oil in it. This one is a little bit pricier and it comes in a beautiful glass Italian blown bottle, but this is one that a lot of people like. Liquid Silk is another option. And then some people just go to some basics like vitamin E oil. Some people have even tried and experimented with olive oil. I even read in the Husband's Guide to Breast Cancer that some couple was talking about using Crisco, but I don't know if I'd recommend that. That one sounds a little concerning to me.

But one of the things you may also want to think about is something that doesn't get talked about a lot is the lubricants that you choose, you might want to consider staying away from the ones that have glycerin as one of the top ingredients. The reason that this is is because there has been some research showing that glycerin has been connected to an increase in yeast infections, in which many of you know that is going through chemo or have gone through chemo, you already are susceptible to higher rates of yeast infections, and you don't want to do anything to increase that risk. So be aware of what products you're using so they don't cause more irritations. We don't want to make sex less appealing than it already is.



If these options are not, you know, the ones that end up working for you, we usually move down the list to ones that include a little bit of estrogen. And for many people this can be a word that is very scary when you've been diagnosed with breast cancer and you've been told to stay away from everything estrogen. However, the STAR study that came out did some research on Vagifem and another estrogen type lubricant called Estring. The Vagifem is something that has these pellets that you insert about two times a week. And Estring is a plastic ring that you insert into the vagina. And they both provide a small, localized dose of estrogen to the vagina, and they help improve lubrication and elasticity, which is something the other lubricants don't really help with. A lot of women aren't aware of what's actually happening in their vagina walls when they're going through chemotherapy and even if they're not going through chemo when they're going through menopause is that those walls become really frail and brittle. They lose that great spongy elastic feeling, and a lot of times can be more susceptible to tears and things that make intercourse really painful. These can really be helpful in rebuilding those walls.

You want to talk to your doctor about it, but they really deliver only a localized dose. It doesn't become systemic or go into the blood stream, so there is no connection or concern with actually causing cancer or even for people that are cancer, estrogen sensitive. So you want to talk to your doctor, of course, and make sure that this is okay, but those are options that you may want to present. I have had some clients that doctors have given them actual estrogen cream, but from the doctors that I've spoken with and oncologists that I've spoken with the creams, they have some opinions that maybe it might be too risky because they're not sure how much is going into the blood stream. So really be aware and be your own



advocate. I think most of you have probably learned at this point, especially when it comes to your sexual health, you really are going to have to be your own advocate; you're going to have to ask questions.

Another aspect here is something that a lot of women especially going through radiation experience called atrophy, which is an inflammatory condition characterized by the drying and shrinking of the vaginal lining. As the body's estrogen production diminishes with menopause, the vagina produces fewer secretions so the vaginal wall becomes less lubricated and flexible, and more prone to tears and cracks like I mentioned before. However, this atrophy and the scar tissue buildup, especially after radiation, can really lead to painful intercourse. A lot of people aren't aware of this fact and they really need to know what they can do to help, you know, protect themselves from this, and also what to do if this happens or you have already gone through this and now you don't know what to do.

One of the first things I'll say is that it's really important that if you're having painful intercourse that you don't continue. That may sound strange coming from a sex therapist telling you not to have sex, but it's really important because when pain continues to be endured as a part of sex, it increases the risk of conditioning a vaginismus (sp?) response, which may sound really medical, but actually it's something that we call vaginismus, and some of you may have heard this term but some of you may not. But basically that's what occurs when the muscles around the outer third of the vagina contract involuntarily when vaginal penetration is attempted during sexual intercourse. So some of you may have recognized this happening when you feel as though your partner goes to enter you and he



can't penetrate. It feels like it's too tight, it feels like suddenly you feel the walls just contracting and you're telling yourself relax, relax, relax, relax, and nothing's relaxing. So this is an indicator that probably you're having some of those involuntary spasms. And it could also be some of the spasms that have been induced by having painful intercourse. So that's why it's important that if you're having painful intercourse you address the painful intercourse immediately and don't continue to have sex. You're not doing your husband any favors even if you think you are. Most of the men that I've spoken to in my office have said that it's not very pleasurable for them when they know their partner's in severe pain or they feel like they've had to completely disconnect from their body or disassociate in order to be there. You know most partners are looking for someone to be present and accessible and enjoy in connecting; that's what sex is really about.

Going back to the atrophy and the scar tissue buildup, some of the things you can do is, that's recommended is using dilators. This can also be helpful if you've already developed a vaginismus. Dilators are essentially just these round, cylinder shaped objects that you can get either at your doctor sometimes, sometimes at a sex toy store, there's also a website called bettersex.com run by the Sinclair Institute, which sells them. And basically you utilize these dilators, and there's different sizes going from very small to larger, and you try and help, you know, stretch out the muscles again, help your muscles learn how to relax again. So if you have atrophy or if you're beginning the process of atrophy that it's important that when you're starting that radiation process you use these to make sure that those muscles don't tighten up, that the vaginal walls don't shrink, and that you maintain that sense of being able to relax and contract those muscles. You can talk to your doctor more



specifically about how to utilize them, how often, more details. But I just wanted to let you know that there are options out there to help you prevent through that process and once you get there.

Another big, a big proponent that I am of this aspect is gynecological physical therapy, which I know that's a mouthful. Some people call them pelvic floor physical therapists. Essentially these are people that specialize in helping women that have had painful intercourse for any of these reasons, or other reasons as well. And they, you know, basically get hands on and help you understand what's happening. They even show you biofeedback, which is really great, on a screen. They teach you how to relax those muscles. They help diagnose you and let you know what's actually happening. They're really well educated most of the time in sexual health, and they have a lot of tidbits and a lot of help that can really help you along the way when you're really struggling or feel like you can't get past the painful intercourse. Some of it as well, as you can imagine, can become psychological, so you know, it's not all physical. And once you have painful intercourse one time often times we anticipate it the next time and that effect just continues to snowball. And part of that can also induce the vaginismus I was speaking of, the spasms, because if you're thinking about the pain that's going to happen your body will naturally protect you by closing up. So there's definitely the physical side you want to work on in learning how to relax those muscles, but also learning how to relax your mind and being able to be present and not having to disconnect from your body in order to be present. You can find a gynecological physical therapist online for somebody in your area. They are limited, but hopefully, you know, you'd at least be able to find someone close enough at a website called apta.org, and



that's A-P-T-A.org, and that stands for the American Physical Therapy Association. And you just look for professionals in your area and try and find one that really specializes in the gynecological physical therapy. If you can't find one, call whoever's on that list and see if they can connect you. Also sometimes sex therapists in your area or doctors that specialize in sexual medicine could be able to give you a referral if you can't find anyone on that list. You should definitely talk to your doctors immediately if you're having pain no matter what.

Another thing that I would like to say about the painful intercourse, or this also applies when we get to the loss of libido, which is the next thing I want to talk about, is being really aware of that it's not your obligation to know your husband doesn't want you to have intercourse with him because you feel guilty or because you feel like you have to or it's been three weeks, or it's been however long. But it is important, you know, that you recognize that he can take care of himself, and most men do. Breast cancer husband is something that Mark Silver, the author of the book about how to be a Breast Cancer Husband, he said in his that breast cancer husbands do masturbate, and I agree, just like 99% of the rest of husbands, they do. So you know if they're really feeling some sexual tension or really need to relieve themselves they can. However, most of the time men, or women as well if you're partnered with a woman, are seeking more than a relief when they're coming to you for intercourse or they're initiating something. They're usually looking for connection. This is why it's really important that you're aware of how you let your partner know that you're not interested, you know, making sure that you don't do any harsh "no!", which is what I like to call them, when your partner's reaching out to you. This can feel really rejecting, and you may find that your partner will stop initiating over time.



These are a kind of an example that I'll use for any of you that are mothers is you know if you have a three-year-old and the three-year-old comes up to you and says, you know, mommy, mommy, I want to go to the park, I want to go to the park, and you just look into their eyes, you know they want to go to the park so bad, but you look outside and it's snowing and they just, you can't take them to the park. So there is the type of mother who maybe would reach out and say, no, we're not going to the park, it's snowing. And then there's the alternative, you know, okay, well unfortunately it's snowing out today. Why don't we color instead? I know your husbands aren't three-year-olds, although some of them may behave like them sometimes, but it is something that I think is really important to recognize that you can come up with compromises. What they're seeking is intimacy, so if they're seeking intimacy and connection it doesn't have to be through intercourse. It doesn't even have to be physical. You can talk about maybe something you can do to just sit down and connect and come up with a list. Come up with a list of options. I've had couples come up with options like things they used to do like playing cards or checkers together, or just something that makes time for the two of you where you can feel connected to each other because a lot of times couples, especially if it's been awhile, there's been long periods of time that they're not having intercourse, they forget to maintain their connection in other ways or get creative.

Your partner definitely needs to know that you still care about your connection and that you want to want to have sex. This will be a big relief. I see this all the time in my office, it's such a shock when the partner hears, especially somebody who says, you know, regardless



of the reason why, I have women all the time who say, I could imagine never having sex for the rest of my life and I'd be happy with that. And then you know they have to actually think about it, and then they think about it and realize, you know, actually they really want to want to have sex, they're just to the point where they don't want it so much that they can imagine a life of not having sex. So it's important to tell your partner that even if you don't want it right now, you would like to regain your desire again, regain your libido. You're hoping to one day feel intimate or the desire to be intimate again.

Let's talk about libido. Let's talk about loss of libido. There's lots of things to be aware of, especially, especially for women that have had menopause induced, or were already menopausal going into their cancer. One of the things that often gets thrown at you is a packet of anti-depressants to make your menopause symptoms go away. And this is something that can be wonderful for treating menopause symptoms, however, often times I hear, well my menopause symptoms went away, but my sex drive went with it too. Also often times most anti-depressants will affect your ability to have an orgasm. So maybe you still have desire but you're not able to achieve orgasm. So this is something to really think about when you make that choice. There are alternatives, there are options, there are things to consider. Some women have had positive experiences with Wellbutrin, adding Wellbutrin to their anti-depressants. Sometimes Wellbutrin has been even shown to induce libido and increase libido, so this may be something to talk about if you're experiencing low drive. Some of the alternatives for helping with the hot flashes or other of the menopausal symptoms may be acupuncture, trying things like primrose oil capsules, exercise, staying away from certain foods like spicy food. And if you have to take anti-depressants or you



choose to take anti-depressants, because I'm not saying everybody shouldn't take anti-depressants by any means, but if you have to there's different options that you may want to talk to your doctor about that are kind of experimental right now, but you know, maybe something to consider.

One of them is called an anti-depressant holiday, and this is where sometimes, you know, I'll have a client and she is unable to achieve orgasm, or he, either one, I've seen both, and only when they're on anti-depressants. So when they go off anti-depressants, they're perfectly capable. So one of the options that some psychiatrists have given them is, depending on the medication, that they could do vacation holidays for two days or three days, let the medication be out of their system, enjoy their sex life during the weekend, and come back to the medication during the week. So this could be an option, something to talk about with your doctors.

Another thing that comes up when we talk about libido and is very controversial is the idea of HRT, and this is something, hormone replacement therapy is what I mean by that, sorry. I'm so used to saying HRT. Things like bio-identical testosterone. And as of right now the conclusions that I've read are that it's pretty much a no-go. It's not been shown to be safe most of the time, but it's something to know and to talk to your doctor about if you're really struggling and you want to just explore it. The reason that it usually has been found to be dangerous is because they think it aromatizes into estrogen in your body. So be aware of that.



Moving onto more of the emotional aspects, you know one of the things that I spend a lot of time with a lot of women in general is focusing on staying in the present. So many women tell me that their mind is constantly racing with things, you know, from to-do lists, from things from their past, predictions of the future, fears, anxieties, and especially when you have something like a life threatening disease or breast cancer or anything else to add to that pile, it just makes this process seem even more difficult. I really ask people to look at their thought process and their cognitions and try and ask the question, how does this make me feel and what does it achieve? You know sometimes we just get so caught in our thoughts and we can't shut off that dialogue. So you know things that you can do to help with that can be doing guided meditations, you know, CDs, podcasts, you know, going to classes where they meditate, going to classes with yoga, just things that help you really stay present and focused on being in the here and the now, especially in a time when there's uncertainty, when you're not sure what's going to happen. If you live in fear of what may occur, then you know a lot of times, I had one woman say to me, she finally got through all the treatments of her cancer and five years she spent worrying about was she going to get a second diagnosis, was it going to come back, and sure enough five years later it did. And she was so angry at herself, and she said the reason she was so angry was because she spent the whole five years worrying about it coming back instead of really embracing those five years and enjoying them. And you know this is really just a testament to even though it's so difficult to really learning that skill, learning to stay present. And you can, if you're really struggling with that sometimes you can get help through support groups, you can get help through going and talking to a therapist.



You know getting support emotionally is so vital. You need to really reach out to people during this time. Like I said, you have to be your own advocate. A lot of people don't know how to support you, and unfortunately you have to be the one to educate them because no book could ever tell them the answers. Yes, there are lots of guides out there and things that can be helpful, but it's your cancer and it's your experience, and they need to know what you need. So you know, even remembering that you have to explain, this is what I need and it's exact, and even if it's just that you need a sandwich on Tuesdays delivered to your house or if it's, you know, that you need someone to walk the dog, people want to help. People want to reach out, they just don't always know how. And especially this is important when we're thinking about emotions because you know the numbers are scary. 20% of people with cancer, is one of the statistics I've seen, have had depression, and so you know we really have to be aware of our cognitions and be aware of our thoughts. This ties into our ability to have intimate relationships because if we're depressed depression becomes part of the relationship, and sometimes it can consume it. It also will definitely put a damper in your sex life and your sex drive, so being aware of how your cognitions and the way you think is going to impact not only how you experience the cancer, but how everyone around you is experiencing it as well.

With that said, the relationship with your partner is one of the most difficult during this time to really figure out how to maneuver because you're just so connected, and they're so involved usually. And the key is really remembering that your partner's going through this with you and going through this as well. Their experience is going to be different, but if anybody is as intimately as involved as you are, or close to it, it's usually your partner, so you want to



include your partner on the decision making process. This doesn't mean that you give control over to your partner of what type of surgery you're going to have, or, you know, what you're going to do, but you just talk to them so that they can feel like they're a part of this process, they don't feel like they're sitting on the sidelines just waiting for you to decide and it's all on your shoulders. This will help you as well to feel like you're part of a team. This is really one of the keys to the communication always, in all relationships, but especially during this time. You know asking more questions and making less statements are always going to be helpful, also sharing your fears and concerns and asking your partner to share theirs. A lot of times I see that a partner doesn't want to burden the person going through the cancer with their feelings because they feel like they should be strong or they should just hold it to themselves, but a lot of you have expressed to me that, in fact this makes you feel rejected or that your partner doesn't care at all because they don't seem to be mentioning any of their fears or concerns. So let your partner know that you need to hear those. Tell your partner, you know, if you just need them to listen. I hear all the time that women are so frustrated with their partners when they hear they're trying to solve the problem, and a lot of men go into that problem solving mode, especially when their, you know, wife's life is on the line or they're going to lose a part of their wife. They get really focused on what's the best solution and the best answer. So it's really important to take a step back and say, you know, honey right now I really I want you and what I need from you is to just listen to what I'm saying. That can be hard sometimes for your partner to learn to do, and you guys can get help sometimes from a third party.



Definitely staying away from mind reading, this is a big one. A lot of couples do this, especially when things are difficult, starting to guess what your partner's thinking or feeling, assume what your partner's thinking or feeling, and that can be really dangerous. We can assume a lot. And if we, if our partner, for instance, reaches out to us to, you know, caress our arm gently and we think, well they must be wanting sex, I know they're wanting sex. Our reaction to that's going to be, if we're feeling not intimate and we pull away, there's going to be a divide there and potentially that the actual initiation wasn't for sex at all, we just read their mind and we got ourselves in trouble. And sometimes they were initiating sex, but we could've had a different conversation about that and come to a different compromise or communicated about maintaining our connection in a way that was positive for both of us. Don't be critical when your partner's trying to help. Try and use positive reinforcement. Remember that he may still be learning some of the tasks that you perfected years ago. A lot of times I hear men are taking on household chores and doing things they haven't done in years or maybe never at all, and you know, it can be really easy to go into critic mode when they put the dishes in the dishwasher improperly or, you know, something as small as that, when really they're trying to help. And certainly when we're going into that mode we're not encouraging them to do more of that.

I think the biggest thing is not letting the cancer consume the relationship. This can be something that happens to a lot of couples. Try to spend some time not focusing on the cancer. You know there's some research showing that it can be negative if a couple spends too much time talking about the cancer and it dominates their life. I've suggested taking maybe a 20-minute break where you have to talk about something else so that it doesn't



consume you. You can do this with yourself too if the cancer's consuming your thoughts. Set aside a time period where you're going to let yourself just stir about, you're going to think everything you want to think about it. But then for the rest of that day you're not. And so however long you need, and maybe you can start decreasing that amount of time. One of the ways, you know, some couples say, well what are we supposed to talk about, there's nothing else to talk about, it seems like it's just on the forefront of our minds. So sometimes I encourage couples to maybe come up with some different topics. They can, you know, make little cards and have little intimate topics to talk about.

I know we're getting close to time and I have so much more I could say. One of the last things I want to say before we move onto the question and answer is that I really want you to also recognize that during this time you know intercourse doesn't have to be intercourse. Everybody gets so linear in their thinking about sexuality, especially because we've been programmed in our culture to think this way: first base, second base, third base, homerun is something we've all heard. And it's not really what sex is about. Sex is about connection. It's about love, it's about intimacy, and that can look a lot of different ways. So you know talking to your partner and getting creative, trying some new things. Just try massages. Just reconnecting with each other physically or emotionally, and going to a counselor can help you come to that. You know so there's different exercises that have been designed, and trying to get away from goal-oriented sex. I do this with my couples that have cancer and couples that don't, and I find it to be some of the most rewarding skills that couples learn is not having goal-oriented sex, but really just exploring each other without judgment and experiencing each other and the emotions that they really feel for each other.



And with that said, I know that I just want to make one last statement. This does not have to be something that destroys the relationship or makes it more challenging. I've seen couples not only come through it stronger, but there's even been research. There was a research study in Canada with couples where one person had breast cancer, and they found that almost half of the couples felt the cancer brought them closer. So it is possible that you can come together through this and actually grow and evolve your relationship.

I also have some books and other websites and things for you, and I'll give you, I'll pass those onto Arline to add maybe to your website instead of listing them off here. But I'm ready for the Q&A, and I look forward to hearing what questions you have for me.

OPERATOR: *And our first question comes from Cindy.*

CINDY: I had a mastectomy five years ago and I did (inaudible). I've been in menopause for three years, and two years ago my husband died of a heart attack. And I've had problems with vaginal dryness before he died. And eventually I think it would be nice someday to meet somebody, but I worry about as the years go on and the, you know, I worry about the dryness. But then I also worry about how do you start a new relationship after you've had a mastectomy, et cetera.

EMILY HARRELL: I think these are very common questions. The things that I would be doing for the dryness is, if you're comfortable one of the things I would explore is utilizing something like Replens that I mentioned before, which is a moisturizer. And maybe



experimenting to see what your comfort level's going to be with some toys or dildos if you feel comfortable trying something out just to see that your body can respond so that you don't have to wait until that first, initial, you know, experiment to see how you feel. And then if you're not feeling comfortable and the Replens isn't enough for you then you can go ahead and move forward with trying some of the other options. As far as, you know, initiating and beginning a new relationship, I think it can be a challenge to have that conversation and to know when, and I think really that's a personal decision, you know, when you feel comfortable, when you feel ready to disclose that to someone is really the right time. And I think you should trust yourself, trust your instinct on when the appropriate time is. I think it is something you should talk about beforehand just because, you know, I think the experience of kind of a shock value if you don't share and you don't communicate ahead of time may leave you feeling hurt or rejected if they're surprised or look surprised. So definitely having a conversation before you become intimate would be my suggestion.

OPERATOR: *Our next question comes from Janette.*

JANETTE: Yes. I was taking Tamoxifen and I wanted to ask you one of the side effects, does that cause vaginal lubrication to be very lubricated, the vagina?

EMILY HARRELL: Yes. There is some, I have read some things that Tamoxifen can actually cause some discharge, you're right. A lot of people are misconstrued and think that it causes their dryness because it's an estrogen inhibitor, but in fact, no, I have read it's



normal for it to cause some discharge. If it's too much you should talk to your doctor about it and make sure that there isn't anything they could do.

JANETTE: Right. Now even though I was having this side effect, I had exactly what you were saying about the radiation. I couldn't have sex; it hurt me very much, and he just couldn't penetrate me. It was unbearable.

EMILY HARRELL: Right. Did you go see a gynecological physical therapist?

JANETTE: No one's really helped me. And then I wanted to ask you does the vaginal muscles get better?

EMILY HARRELL: They absolutely can, and that's what using the dilators can be helpful at home. But really the biggest thing I'm a big proponent of is the gynecological physical therapy.

JANETTE: You see my, she did not help me at all.

EMILY HARRELL: But did you just go to your regular gynecologist? Or was it a physical therapist?



JANETTE: Well you see I had problems. I had a cyst, that's why I went to the gynecologist. She thought I had cancerous, a tumor. And then that was the gynecologist I was seeing at the time.

EMILY HARRELL: Yeah, because it's not actually your gynecologist. It's actually a physical therapist that you go see and they retrain your muscle –It's a gynecological physical therapist.

EMILY HARRELL: Yeah, and that's who I want you to see because they can make tremendous, especially with the vaginismus, which is what you're kind of describing, that tightening up, and you may have some scar tissue and some atrophy. And they can help you –

JANETTE: Does the scar tissue go away?

EMILY HARRELL: The scar tissue won't go away. But you can do things to help your body respond better to that scar tissue.

JANETTE: So this was mainly due to the radiation?

EMILY HARRELL: Most of the time it is due to the radiation. Sometimes you may have already had a little scar tissue built up if you had children vaginally.



JANETTE: No, I didn't.

EMILY HARRELL: But usually it's due to the radiation process.

JANETTE: You see the gynecologist was telling me it was due to menopause. She didn't say anything about the radiation.

EMILY HARRELL: Well you may be experiencing, I don't know because I can't look at you -- experiencing, you know, that the walls of your vagina are too frail and too brittle because of the menopause. And that could really be helped by something like the VagiSim or the Estring I was talking about.

EMILY HARRELL: So those, the estrogen can really help rebuild those walls. So if that's what's happening then definitely your gynecologist should be able to give you one of those options.

JANETTE: You see it was someone that I was going with and I had a very bad experience. After that he just left me. Can you imagine that?

EMILY HARRELL: No, unfortunately I can. I'm so sorry to hear that.

JANETTE: Yes. Well you've been very helpful. I really appreciate it. And you think it can get better?



EMILY HARRELL: Yes, absolutely. You know vaginismus is one of the most treatable sexual dysfunctions – that’s part of your problem. It may, the vaginismus probably stemmed from painful intercourse, which may have been due to either the lack of estrogen in your walls or –

JANETTE: The radiation.

EMILY HARRELL: -- potentially some scar tissue buildup from the radiation –So you know you want to get a really thorough medical exam, and somebody who’s going to be a sexual advocate.

JANETTE: And you said it’s gynecological physical therapist?

EMILY HARRELL: Yes. And you can go to APTA, A-P-T-A.org –

JANETTE: Right. I didn’t know there was a gynecological physical therapist.

OPERATOR: *Thank you for your question. Our next question comes from Heather.*

HEATHER: Hi. My questions, some of them have already been answered . But I’m also single. I had a very aggressive breast cancer and a double mastectomy, and lots of various side effects from my treatment: lymphedema, neuropathy and stuff. And how do I, I just feel this tremendous loss of libido or feeling sexy, you know? The thought of even going out with



somebody is just , you know because I don't even feel just there. And I have some of the problems that people have been talking about. I went to the gynecologist and was really shocked. I'd never had a painful visit, and then she said that my, you know, vaginal wall was brittle and dry, and it was very, she had to use this like really tiny speculum. So but just, you know, I think it's that I've had to change the clothes that I wear and all sorts of things.

EMILY HARRELL: I think this is really common and there's lots of different things I would say. You know the biggest one being that the only thing that you really we know for sure you can control is your perspective and the way you --- think about things. And I know it's so hard to do and so easy to say. But the more that you can really start to think about all of the positive qualities that you hold, all the things that make you beautiful, all the things that make you attractive, and step away from all of these images and thoughts that have been put into your mind about what beauty is and what sexuality is, and what sex is, the more sexual you're going to be. The more satisfied with yourself you're going to be. And maybe starting to experiment with some self-stimulation and seeing, you know, just getting away from being so scared of your body. Starting to just massage your body, touch your body; explore your body, and starting to kind of fall in love with it again. And find new joy and new passion for it. And I know that can sound really difficult, but it's something that you do step by step, and you just slowly start fighting each negative cognition as it comes up, you know, and just starting to try and replace it with a positive. And honestly, your loss of libido can be stemming from lots of different things. It can definitely be psychological. There can be hormonal things happening there. But the one thing you definitely can control is the



psychological aspect. That's something you can certainly learn to shift your thinking. And you know I think there's, one of the things that, you know, when you really feel stuck that can be best is going and seeing a therapist. Talking to a therapist who's really going to be an advocate for you and help you find ways to fight those cognitions because a lot of them have been planted in your mind by yourself, and also by our culture and the people around you, and potentially previous relationships. And so, you know, dissecting them and really learning to embrace the present and who you are now, and who your body, how your body looks now. Does that make sense?

HEATHER: Everybody says that I've had a positive attitude. You know I think I've moved on in some ways, but I think because of the array of physical problems that I've had, I think it's the physical aspect that's so difficult.

EMILY HARRELL: Right.

HEATHER: And I just started masturbating.

EMILY HARRELL: Good.

HEATHER: But, you know, I don't know if there's anything else like you had mentioned standing in front of a mirror and trying to pick out positive things. Is there any other sorts of things that, you know, that you would suggest concrete or –



EMILY HARRELL: Anything that you can do that helps you engage with your sexuality. So even, you know, I don't know where you live, but I live in Chicago, and in Chicago there are classes you can go to that really help you engage with your body. There's Flirty Girl Fitness and things that are really fun and lighthearted that help remind you that you can still be sexual and sexy and feel sexy and move your body in sexy ways. You can take private classes if you feel self-conscious at a lot of these places. So you can look in your area and see if there's maybe someone who does burlesque classes, and some, I know that stripteases are all the rage now for learning how to pole dance. Some people are going crazy on that. But you know anything like that that can kind of push you outside your box, you know, even if it's just, maybe if you feel really sexy when you do ballroom dancing, even things like that. But just getting physical with your body again, and you know, in a way that feels comfortable and safe for you, and trying some new things. Explore. You know, step outside your box.

HEATHER: That's interesting because I used to do some of those things when I, you know, before cancer, and I –

EMILY HARRELL: Yeah.

HEATHER: -- wasn't thinking about doing them now Thank you.

ARLINE KALLICK: I think we're going to have to go to our last question.



OPERATOR: *Our last question comes from Linda.*

LINDA: I'm 46 years old. I've been in a lesbian partnership for 11 years. I had a full hysterectomy at the age of 40. I had a very invasive breast cancer. I was diagnosed with a stage 3 at age 41. I had a radical mastectomy, and my tumors were estrogen positive. So I cannot take any estrogen. And I recently had a second mastectomy for symmetric reasons to make me even.

EMILY HARRELL: Right.

LINDA: They won't, I asked for testosterone. They won't give me any testosterone unless I'm taking inhibitors such as Arimidex or Tamoxophin, et cetera, et cetera. But my body can't tolerate those inhibitors because of the bone pain. So my question is, is there anything that I can do because I feel like I have just been stripped of my sex life, and I don't feel it's fair to my partner. And although she's very faithful to me I don't want to lose her. And you know I just feel like, you know, you mentioned Replens as a lubricant, but I have no libido at all. So anything you could suggest would, you know –

EMILY HARRELL: Right Well you know some of the options that I was mentioning before could be things you could explore. Another thing that maybe would be helpful is, I didn't really get to it, but there's some sex therapy techniques that sometimes help induce libido, and they help women and men as well, whoever the person struggling with their drive is, kind of step away from the anxiety that can sometimes be involved with the touch leading to



some type of intimacy that they're not desiring. It's called sensate focus, and they're exercises that you and your partner can use to kind of re-engage with your touch. There's different steps and different levels. There are exercises that were originally created by Masters and Johnson, famous sex studiers. And you can look it up online if, do you have a computer? You can just Google sensate focus and there'll be a bunch of different versions and varieties. But that may be something that you might want to try.

EMILY HARRELL: Sure. It's S-E-N-S-A-T-E. Focus.

LINDA: Okay. Did I mention I have, suffer with vaginal atrophy also?

EMILY HARRELL: No, you didn't, but that is certainly something you could be doing for that would be the dilators or seeing the gynecological physical therapist or both. I would recommend both. And usually if you see a physical therapist they will recommend dilators.

LINDA: I'm on disability. Would these types of physicians take Medicare?

EMILY HARRELL: I'm not positive. It would depend on the people in your area.

EMILY HARRELL: You would have to look them up and see. Just give them a call and see. And sometimes, you know, sometimes they do and sometimes they don't. But it might be. And maybe you'll need a referral and that might be enough.



LINDA: Right.

EMILY HARRELL: But the biggest thing too, you know, if you try these things at home and they don't work for you, I would suggest that you contact a sex therapist in your area, and go and meet with them and see if the two of you can come up with some ways to make sure that you're maintaining your connection.

LINDA: The problem with that, too, is I would not feel comfortable with a man. And I don't know, our area here, I live in the Fort Worth, Texas area. It's a pretty big area, but I don't know if there's any women in that field in this area or not.

EMILY HARRELL: Well you can look online at, it's called the American Association of Sex Educators, Counselors, and Therapists. Website is: aasect.org.

EMILY HARRELL: And if you look on there you should be able to locate some professionals in your area. And even if it's a man, maybe he can find a woman for you.

LINDA: Thank you so much.

EMILY HARRELL: You're welcome. Thank you. Good luck.

ARLINE KALLICK: This is Arline again. At this time we'll have to end this portion of our call, although it could go on all night long. And thank you Emily so much for your insightful



and excellent presentation. Because the generosity of healthcare professionals like yourself it's possible for the Network of Strength to provide useful information and assistance through the breast cancer journey. And we thank you for your beautiful program this evening. And I'm sure I would encourage everybody to read the transcript when it's online or listen to the podcast because Emily said a lot of very, very useful information for all of us. So thank you so much.

EMILY HARRELL: Thank you.