Navigating Dual Roles:

Balancing Your Love Life and Cancer Caregiving.

With Dr. Lisa Fine

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Sharon Levine:

Good evening. Welcome, and thank you for joining us for tonight's webinar, Navigating Dual Roles: Balancing Your Love Life and Cancer Caregiving. Tonight, we will focus on ways to find balance, foster communication with your partner, and find time for self-care. We are lucky to be joined by Dr. Lisa Blum, who I will introduce later in the webinar. I'm Sharon Levine, Illinois program coordinator at Sharsheret. I want to take a moment to thank our Sharsheret webinar sponsors.

Thank you to GSK, Daiichi-Sankyo, Florence and Laurence Spungen Family Foundation, and the Cooperative Agreement DP24-0061 from the Centers for Disease Control and Prevention for supporting tonight's specific webinar. Before we begin, a few housekeeping items. Today's webinar is being recorded and will be posted on Sharsheret's website along with a transcript. Participants' faces and names will not appear in the recording. If you would like to remain private, you can turn off your video and rename yourself, or you can call into the webinar.

Instructions for both options are in the chat box now. You may have noticed all participants were muted upon entry. Please keep yourself on mute throughout the presentation. If you have questions for the speakers, put them in the chat box either publicly or click Sharsheret in the chat box to submit a private question, and I'll ask them throughout the program. We receive many questions in advance of the webinar and anticipate receiving many questions in the chat box. Please make sure to ask general questions, as we can't offer specific medical advice. We will do our best to answer all questions.

For those of you who are new to Sharsheret, we help women and families facing breast and ovarian cancer, as well as those who are at elevated genetic risk, through free, confidential, and personalized support and resources. In addition to the virtual services we offer that can be found on our website or by emailing us, you can also access prior webinars on a range of cancer-related topics, as well as access our calendar of upcoming virtual programs through our website.

My colleague is putting in the chat the direct link to our previous webinars. At Sharsheret, we also help caregivers. Being a caregiver is often a challenging experience, and when you add the complexities of maintaining a loving relationship with your partner, it can feel even more overwhelming. Thanks to the generous support of the Florence and Laurence Spungen Family Foundation. Our Spungen Foundation Family Focus Program helps you support your loved one affected by breast or ovarian cancer.

This free program allows you to speak directly with one of our skilled social workers about your personal questions and request a free caregiver information packet that includes resources from Sharsheret and other cancer organizations to help you understand the diagnosis and treatment of breast or ovarian cancer and the support options available to you. As we move into the webinar itself, I also want to remind you that Sharsheret is a national not-for-profit cancer support education organization and does not provide any medical advice or perform any medical procedures.

The information provided by Sharsheret is not a substitute for medical advice or treatment for specific medical conditions. You should not use this information to diagnose or treat a health problem. If you have any questions that are specific to your medical care, the doctors will not be able to advise regarding specifics and would advise that you speak to your medical provider. Always seek the advice of your physician or qualified health provider with any questions you may have regarding a medical condition.

Before we hear from Dr. Blum, I have the honor of introducing our first speaker, Mike Kanarick, who is here tonight to share his personal experiences and insights. Mike, who is a father to three teenagers, a spouse, and a Sharsheret volunteer who recently ran the New York City Marathon, added cancer patient caregiver to his long list of life roles in 2022 when his wife was diagnosed with breast cancer. Mike, thank you for joining us here to share your experience as a caregiver.

Mike Kanarick:

Thank you. It's great to be here. As you said, my name is Mike. I'm joining you this evening from Shelburne, Vermont, near Burlington. By the way, that's our ketubah in the background. That's intentional.

30 years of marriage. It's great to have Liz with me and to have her with me for many more years. And it's really humbling to be here to share our story with you, and I say our story because it's not just about me as a caregiver. It's about my wife, Liz, and I'm totally going rogue right now.

I don't even know what the Sharsheret leadership is going to do, but I just wanted someone to say the quickest hello to you. Come here, Lizzy. All right, quick cameo. There's Liz.

Liz:

Hi you guys. I'm not staying around for this. Don't worry. I know this is caregiver-oriented, but I love Sharsheret in general, and I love that there's so much support given to caregivers because I think often an underappreciated and under-supported role and Mike gave me so much support and care, and it's just great knowing that caregivers are not left entirely on their own. So thank you, Mikey. Thank you, Sharsheret, and y'all have a good call.

Mike Kanarick:

Thanks, Lizzy. I hope I'll be invited back after that. So-

Liz:

[inaudible 00:06:25].

Mike Kanarick:

... I want to start by saying that I realize that each of us is unique, and so, as caregivers and lovers and partners, our paths for tackling cancer journeys as a partner, as a caregiver are all going to be unique. And so by joining you tonight, I hope in a very humble way that maybe by sharing our story, you'll come away from the conversation with maybe an idea or two that helps you in your journey as a caregiver or in your journey helping anybody who's dealing with cancer. So I wanted to set the stage.

January 18th, 2022 I wake up. Liz, who you got a good sense of, she's awesome. She's pretty funny too. She said in the morning, "The kids are going to school, I need you to feel my breast." And I said, "Wow, this is going to be a great morning." She said, "No, no, I'm serious. There's a situation." Liz was 52, I was 53 years old. She had some kind of a lump on her breast. That was day one. The next day was a mammogram and an ultrasound. Two days later was a biopsy. Three days later was a cancer diagnosis. So from one moment to the next, everything changed and Liz had a tumor on her right breast.

The cancer had spread to the lymph nodes under the arm, and we were off on the cancer marathon, pun intended. We have three kids, as you heard. At the time, our girl-boy twins were 17 years old. They were high school juniors. They were starting to think about where to apply to college. Our younger daughter was 13 and in seventh grade, and it was a scary time. Less than a month later, on February 18, Liz's first chemo treatment. Two days later, at Liz's insistence, I left the house with Liz here with our 13-year-old and friends and neighbors close by because we had plans to take the big kids to visit colleges.

And Liz said, "That's got to happen. I don't want my cancer diagnosis to prevent our family from doing what we're going to do." And I'll talk more about communication in a moment, but this was just an example, early on, of making sure we understood each other and what was important as Liz was on her way to fighting cancer. At the time, Liz was brand new in a job. Three weeks in. Liz is an attorney, and she had just started working in-house as a lawyer at a company, very conscientious, wanted to keep working, and somehow worked for seven months through chemo and surgery.

Don't know how she did it with a foggy brain from time to time. It was incredible. But eventually, she stopped working because it was just too much. She was dealing with extreme fatigue, and it was really tricky. But like so many people, when this all happened, we were living lives like many of you, very fulfilling, busy times, always trying to keep all the balls in the air. Kids with their sports and other activities in school, volunteering at our synagogue, and a lot more. And so that kind of sets the stage. I want to talk about really quickly three key themes.

Fostering communication, emotional wellbeing, and finding time for self-care. All three of which helped me, helped Liz, helped our family as we dealt with this cancer journey. Liz and I had a really solid foundation. We've been hanging out since 1985. We met on a summer trip to Israel as teenagers. We'd been married 27 years at the time. We had 10 years of marriage without kids. And so we really did have a good strong foundation. We were already in couples counseling. Fortunately for us, no relationship-threatening issues, but maintenance, strengthening our relationship.

We believe in talk therapy, and I'm not saying all of you should do that, but it's something to think about. It was amazing. It was helpful before cancer and during. It just gave us even more resources for how to communicate with each other and do well, and be there for each other. I think one hugely important suggestion I can make is be a good listener to your partner. I found that by asking Liz what she needed and then trying really hard to listen well served as a winning combination.

There's so much I wanted to do, and so much I wanted to say, and so many ideas that I had, but I needed to make sure I was listening and hearing Liz and really trying to find a balance. Like probably all of you on the call, if you have somebody with a cancer diagnosis or God forbid you do later, you just want to do everything you can to help make that person better. And so, I mean, I'm hearing a little bit of an echo. I don't think it's me, but maybe someone's not muted.

Sharon Levine:

Is it-

Mike Kanarick:

Am I good here, Sharon, to keep talking?

Sharon Levine:

... possible your wife's computer's on?

Mike Kanarick:

Hello? Hello?

Sharon Levine:

Is it possible your wife's computer's on?

Mike Kanarick:

No, she's not on one. It's better now. Sorry about that, folks. So we... So anyway, being a good listener, finding a balance. In our case, Liz wanted help, but she didn't want to be smothered, and we talked about that. She's a very strong and independent woman. So I tried to find a balance of taking good care of her but not treating her like a sick person. It was bad enough that she was sick and dealing with things, and it didn't always work. Sometimes, she had to say, "I don't need that right now."

And I had to have a thick skin and know that she wanted my help. She loved me, I loved her, but we just needed to try to find the balance, and there's no perfect recipe. And she's funny. She just said, "Oh, this is such a tough time. It's like..." And Liz is very cerebral and intellectual, but on a base level, she was funny too. She said, "I can't believe this. My boobs, my hair, my body size, everything's fucked up. What am I doing here?" And we would laugh, and we would cry, and we would just try our best to move forward. Pardon my language. Just trying to keep it real. So that's communication.

Emotional wellbeing. I would say one of the best things that we did was being comfortable asking for and accepting help from friends and family. I'm pretty good at that, anyway. I like to give help. And I think because I like to give it, I'm fine asking for it. I feel like what comes around goes around. Liz and I grew up in different towns, went to different colleges, went to different grad schools. We're very blessed to have a lot of friends and loving family, and people were there for us. So leverage your connections. If people say they want to help, take them up on it.

If they want to make you dinner, start a meal train, go for it. If they want to send cards or if they ask what you need, ask them to drop by flowers. It brightens up the room. Every little thing matters. We even had one... two couple friends of ours, these four folks who came over the night before chemo every time. And here's... If you leave with nothing else from this conversation with me, and I promise I'll end my portion soon, find these socks online. I'm not going to say it out loud, but we have these great friends who brought a care package over the night before Liz had chemo every time with socks that she could wear to chemo.

It was the best thing. It was funny. She looked forward to it. They put other fun stuff in there. Her mother sent a Strong AF glasses holder. I mean, pamper your partner. Make sure they have fun stuff. Make them laugh. Just take care. Take care of your emotional wellbeing. Finding time for self-care. So we're talking about communication, emotional wellbeing, and finding time for self-care. I'm wrapping this up. It's so important if I'm going to help Liz, and for me to help Liz during that time, I had to take care of myself. It's like the oxygen mask on the plane. You got to put it on the grown-up so you can take care of the kid.

So I like to run, as you heard. I like to ski. Liz got sick in the winter. I live in Vermont. And while making sure Liz had everything she needed at any moment, I kept getting outside to go running. It's my therapy. I got out for a couple of hours here and there on the ski slopes. Being on the mountain is one of my most happy places when I'm not with my family, which is my absolute happy place. And it was just so important for me to get out and to be out and take care of myself so that I could be as strong as I could for Liz. And those three things I just talked about, and this is the last key point, helped me be, I think, and I say with humility, a better caregiver.

All of that stuff helped me be there for Liz. One significant role that I played, and it was awesome, and love you, thank you, Sharsheret was: Liz's chemo is the kind of chemo that would make your hair fall out. There's something called cold capping. A lot of you may have heard about, some may not. You basically freeze the scalp before, during, and after chemo. You fool the chemo drug. I picture the chemo coursing through Liz's body, and they get up to about here, and they turn to each other and say, "Holy smokes, it's freezing up there. Turn back." And they don't go up, and the hair stays in.

And therefore, Liz was out and about feeling like crap inside sometimes and emotionally dealing with this but she didn't necessarily look sick because she had her hair, and people didn't look at her and necessarily know she was sick. And so this was really helpful. Sharsheret was awesome to do it. And the last point I'll make is that I asked Liz before tonight's webinar what some of her words were beyond what she just shared with you about my role as a caregiver. And Liz said, "I felt cared about and cared for by you, but I didn't feel like you were only my caregiver."

Liz said, "We found ways to stay connected as best friends, as lovers. We found activities together. We did a lot of streaming of Netflix." That was our in-the-house date nights. And she felt like she had freedom to take care of herself and to heal, but she had the help she needed as well. And the help came not just from me but from our kids and I from our friends. And so I'll leave it at that. Thanks for the opportunity. I'm looking forward to learning from Dr. Blum as well.

Sharon Levine:

Thank you so much, Mike. And thank you for Liz's guest appearance. It really means a lot that you are able to share your experiences, and it means so much when you can hear from someone directly who went through it. And thank you so much for all of your tips and life experiences.

Now, I am pleased to introduce Dr. Lisa Blum, a licensed clinical psychologist who specializes in promoting healthy couple and family relationships. Dr. Blum co-founded the emotionally focused Couples Therapy Resource Center in Pasadena, California, which is one of the only research-validated therapies that are used to help couples and families strengthen relationships and build stronger connections. I turn your attention to Dr. Blum.

Dr. Lisa Blum:

Thank you. Thank you, Sharon. And Mike, thank you for that beautiful talk. I feel like I want to step aside and let you continue the conversation because the things you had to say there were so incredibly important and helpful and fit really, really well with the things I was going to say, but it has so much more meaning when it comes from you. Thank you for sharing your experience. I hope to share a few things with you tonight.

Much like Mike said, some of which may be helpful to you. As you heard, I'm a clinical psychologist. I'm in private practice in Pasadena. I'm over 25 years in practice, and I work predominantly with couples but also with families and individuals. I am not a cancer survivor myself, but I have lived with cancer in close loved ones in my family, and I have worked with many couples who are dealing with a cancer diagnosis or other major health crisis similar.

And what I hope to offer tonight is some insight on some of the changes that might be taking place in your relationship with your partner because of the crisis that you're both facing together, but also some strategies and some practical ideas, much like Mike had, mainly around communication also because that's so important, around self-care because that's so incredibly important. And also, hopefully, we'll have time to touch on some things that may be impacting your sexual relationship as well. Also, incredibly important.

In a webinar like this, my comments have to be general by nature, but I hope that some things will resonate for you and some may not. And there's nothing here that I'm saying that is anything that you're supposed to do or should feel or anything like that. You'll know what can work best for you and your partner. And so I hope that you'll take anything that might be helpful to you and leave the rest. So, with that, I'll just let you know that I'd like to start in a moment with just some basic facts about caregiver stress.

I'd also like to talk a little bit about the framework that I use when I'm helping couples keep their relationship really strong. And that's an attachment perspective on relationships. Attachment is really just the fancy word for adult love and bonding. And I want to explain just a little bit about that framework because I think it helps to make sense of some of the things that I'm going to share with you, which perhaps could be a little surprising for what my recommendations are.

We're going to talk about some really practical strategies about communication and handling big emotions and taking care of yourself and, as I said, sexuality. So we'll get to as much of this as we can. So, let's go to the first slide and let's talk about some of the biggest burdens for cancer caregivers. And I'm sharing this slide not to hammer home something that you already know, but really I hope to validate that the things you are experiencing as a caregiver for someone who has cancer are really very real, very universal, very shared amongst people in your similar situation.

And so as you can see here, this is from a recent study in 2024. These were the biggest burdens kind of in order of how many people endorsed that this was one of the big burdens. So grief was one of the biggest ones. Mental health struggles for the caregiver. Particularly over half caregivers said, "Yes, I'm dealing with anxiety and depression as a result of this crisis we're going through." Physical health issues in the caregiver, particularly fatigue and loss of sleep and loss of good rest.

The financial burdens that come with job changes, job loss, time off work, all the cost of treatment and care, lost time, lost social life, and a number of other factors as well. So again, I'm sharing this to say that not only in a cancer crisis is the person with the cancer so deeply affected, but you, as the caregiver, are also profoundly affected, and this can have profound effects on your relationship as well. So next slide. By the way, I want to say one thing. I am going to pause at intervals for questions and comments, so I'll do a little bit and then we'll take some comments.

So when I talk about an attachment approach to understanding your relationship, what do I mean by attachment? And two of our favorite friends here, Piglet and Poo, can help us understand this. So Piglet sidled up to Poo from behind. "Poo," he whispered. "Yes, Piglet? Nothing," said Piglet, taking Poo's paw. "I just wanted to be sure of you." This is the essence of attachment in adult love. "I want to be sure of you. I need to know you're there with me." So we can go to the next slide. There are a couple of things that are really important in understanding about an adult relationship.

Love is this dynamic state, meaning it ebbs and flows. It changes. That's why it's on a balancing board involving both partners needs and capacities in three areas. They sort of call these three systems in a relationship. One at the bottom, there is attachment and love, how we connect with each other and feel like I can be sure of you. Another is caregiving. Caregiving is a part of adult love relationships as well as sex. And all three, both people have both needs. So one of the things that happens when there's cancer is that this balanced board right now shown as balanced can really get out of whack. Let's go to the next slide.

"It really helps to know that love is one of our most basic needs from the cradle to the grave," meaning we never outgrow the need that we have for closeness with our significant other. When we're a child, it's the parent, obviously. But when we're an adult, it's our partner. We need them like crazy like a child needs a parent or a caregiver. And sometimes, we don't understand this. Can you go to the next slide? When we are threatened with any kind of loss or isolation from this most important person in our life, we experience something that is hardwired into our brains that is called primal panic.

To feel disconnected or separated or potentially losing our most precious loved one is inherently a traumatizing experience. And so, of course, there's nothing like cancer, which is a life-threatening disease. Not in every case, not every time, but can be. It's terrifying the thought of losing our loved one. And that's true for both people. So you have both people walking around in a traumatized state when there's a cancer diagnosis, and as Mike said, "It's so out of the blue. From one moment to the next, the world can change." Next slide.

I'm sharing these because it's going to really help to have a framework for some of the things I want to say next. So I'm just sharing a few moments of trying to understand what's happening in the relationship. So when there is a felt sense of loss of the connection and security in the connection between the two partners, it can feel like this. It can feel like individuals just out on their own island in the middle of the sea. And it can have significant impacts not just on our mental health but also on our physical health and sense of being okay in the world. Next slide.

A secure connection between the two partners is the thing that is really the healing element. It's what offers us what's called a safe haven and a secure base. So a safe haven is that really comforting person and place that we can run to when the world is really scary and threatening, and the secure base is the place at home that we can start from where we feel like we have love and safety and encouragement and connection and that makes us bolder to go out into the world and explore what we need to explore out there.

So making sure that the relationship between the two of you can continue to be that safe haven and secure base for both of you is kind of at the heart of the comments that I'd like to share. Next slide. One of the things that happens in our particular Western culture, though, is that we really misunderstand this need that we have for closeness and connection. In our culture, we're really big on independence, and don't be codependent, and a lot of negativity around really needing someone else. We tend to think that our needs for our other person are shameful or that it means we're weak.

And I'll give you a really practical example of how this shows up. I'm working with a couple right now, a lesbian couple where one of them is dealing with a cancer diagnosis, and her partner, in an attempt to also take care of herself, is trying to continue some of her social activities. She did an activity that... this past weekend that was a little further away from home than normal, so it meant a longer commute, both forward and back, and the activity itself was a little longer.

So the partner was gone for the full day on Sunday, and the partner who's dealing with the cancer diagnosis had such a hard time being able to tell her partner, "You being gone for a full day when I'm going through all of this is too hard for me. It feels too long, and I get too lonely, and I get too scared. And a whole day of you being gone is hard." She couldn't tell her partner that because of exactly this statement here that she thought that meant she was being too weak, and too needy, and too dependent.

And so what happens instead, these feelings come out sideways. And when the partner came home from the social event, she was met with a whole lot of anger that she had no idea why because these kind of things about these needs are so hard to be able to talk about. Next slide. So what is it that helps us feel that safe haven and that secure base? How do we assure that that's what we're creating with our partner? And it has to do with these two aspects of accessibility and responsiveness.

So what does that mean? Accessibility means, "If I need you when I need you, can I reach you? Are you there?" And responsiveness means, "Can I trust that when I call out for you, you will turn and respond to me, that you'll engage with me, that I will matter enough and be worth it to you to come and respond." So these are the two things, accessibility and responsiveness that really help to build that security and the relationship. Next slide. Okay, so that's the little bit of the spiel that I wanted to give because it's a background for really helping to understand what's going on.

When there is a cancer diagnosis or a cancer threat or other serious diagnosis, this puts your relationship under so much strain. So, like Mike was sharing with us, you were in pretty good shape with Liz before this cancer diagnosis started. If you're lucky, that's true. Sometimes that's not the case. Sometimes, you're in the middle of dealing with all of life's difficulties, with all the daily stuff and the kids and the in-laws and the finances and the chores and the dog.

And sometimes, your relationship isn't in the best place when the cancer diagnosis hits, which puts an even greater strain when you're facing this existential threat. And the thing that doesn't get acknowledged so much is that it's a threat of loss in your relationship for both of you. You're both worried about losing the other. Maybe the partner is worried about losing their partner to cancer, but maybe the partner with cancer is worried about losing their partner because, "I'm going to be too much. This is going to be too much."

So both of you are under this threat of loss, and it's easy for there to be primal panic that comes up for both of you. There are really two crises that are happening when there is a cancer diagnosis. The first crisis is your partner has cancer. That's a big crisis. But the second crisis is you have a partner who has cancer, and that's really scary. So what do we do when we're under strain when we're in a relationship, but it feels like there's this threat to it? What do we do?

Can you go to the next slide please? Human beings have a really limited number of ways. For all our complexity and our sophistication, we have a really limited number of ways that we deal with disconnection or the threat of disconnection and this tends to divide about equally in the population. About half of us, when we're feeling not so securely connected to our partner, turn up emotion to try to get back to safe ground.

Sound the alarm, raise the red flag, talk about what's wrong, talk about how we're not connected, maybe get angry about it, maybe pursue and insist that, "We have to fix this. We have to spend some more time together. We have to go to therapy. We're in trouble. We need help." That's the turning up of the emotion. About half of the people deal with significant threat and the possibility of loss by turning down the emotion in order to try to get back to safe ground. So if things aren't feeling very safe, "Well, that's kind of scary.

I don't want to delve into that and talk about that even more or call attention to the things that don't feel very good right now. Let's just get along. Let's just watch a movie together. Let's just not talk about it." That's a way of trying to turn down the intensity to get back to safe ground. And so this can set up quite a conflict between partners where one is trying to raise the roof and say, "We're in trouble, we need some help." And the other one is trying to say, "No, no, no, we're fine. We're fine. We can just deal with this. We're okay. Let's not make such a big deal."

And so this can set up some really negative interaction patterns between couples who are both... both partners are trying to deal with a very significant crisis. So what's the antidote? Next slide. It really is about, and this is sort of the bottom line of a lot of what I'll have to say tonight, that our ability to bridge across this divide and the different way that we can each deal with significant emotion and threat and loss is really to be able to reach out for each other. That our uniquely human capacity to seek calming and comfort from someone we love and trust is really our strength.

And actually people who are going through crisis, kind of as Mike referred to, who can reach out to those support networks and really accept a lot of love and connection are the ones who get stronger. And the same is true in our most important romantic relationships. Reaching out to each other through this is what's really critical. Next slide. Mammals know this, that what we do when we feel disconnected, if we can reach for each other, that's what makes all the difference.

And so, if you're wondering right now if I'm saying if you, as the caretaking partner, should really be reaching for your partner as well as letting them reach for you, I am saying yes. Actually, your partner also wants to be able to care for you even while they're going through such a difficult thing. Because when you pause to think about it, if you are caring for somebody and they're accepting your love, that is really a way that you can feel important, that you can feel important and feel of service and know that you're offering some calming comfort to your partner as well.

Both of you need this. So some of the specific strategies that I'd like to share with you now really have to do with ways that you would be able to offer each other this comfort and care as way to get through a really stressful situation. Can you go to the next slide? I'm not sure if I want it right now. Okay, let's go back. I'm not ready for that one yet. So what does this mean? How do we do this? How do we reach for each other? The most important things when we're under threat are care and contact and comfort. So finding ways to turn to each other with any of those things is really what matters.

What are the manageable sources of support that your partner... that you can allow your partner to offer to you as the caregiver? So let me be clear here. I'm not suggesting that the caregiver lays all their burdens at the feet of the person going through the crisis of cancer. I'm not suggesting that. What I am talking about is in your role as caregiver, where you are doing a lot of additional physical labor, emotional labor, probably financial labor because maybe the person with cancer needs to take time off work, and you are the income earner right now.

When you as the caregiver are doing all this additional kinds of labor, what are the manageable and reasonable ways that you can allow your partner to give back to you? That you can allow your partner to express their deep care and love for you? What care, comfort, and contact can they offer? Is it okay to ask your partner with cancer for a hug, for a neck rub, for them to tell you in moments when they're feeling stronger, "We're going to get through this together? We're in this together." Can they tell you what you are doing right all the things that you are doing to care for them?

So there are lots of ways that we can accept love and care and support from our partners who have cancer. And this is really important because it's the two-way street that keeps the relationship strong. So, of course, I'm not saying that the partner with cancer who may be going through chemo and feeling terrible should be the one to go out to the supermarket to get the groceries this weekend. Of course, that's not what I'm saying. There are certain roles that, as the caregiver, you will have to do because your partner really can't.

What I am saying is let them give you the love, the connection, the comfort that they can give so that they can still feel like your partner in this endeavor and in this struggle that you're both going through. One last piece, and then I'm going to pause and let you have any reactions that you want. We'll go to the next slide now. All of us do need to be heard, and Mike spoke to this as well. How important listening is when there's so much going on. And again, this is a two-way street.

When you're facing something as big as a cancer diagnosis, the feelings that come up can feel like this depiction here, absolute tidal waves. The terror, the anger, the sense of betrayal of your body, the feelings of shame of what's happening to your body, the feelings can be big, really big, and they can feel like they threaten to overwhelm. But one of the biggest ways that you can really turn toward each other is by being able to be present for these big wave feelings.

Many of us fear that these big wave feelings are going to overwhelm us and that we're going to drown or that we're going to be stuck there forever, but the truth is we're not. Feelings, they rise, and they fall again. They crest like a wave, and then they ebb, and they go back out. And if we can be present with each other for the big feelings, that really gives a sense of connection and of care for each other and of that balance of how we stay connected.

Caregivers often feel like they need to put on a brave face like they can't share what they're going through or how hard things are for them. Sometimes you can't. Sometimes, it's not the right moment. When your partner with cancer as at a real low, that is not the moment that you can come and say, "Well, let me tell you how hard it's been for me too." So I'm not talking about just doing this anytime, but I'm talking about there being moments when it is okay to say, "I'm really scared too. Are you scared? Tell me about how you're scared and I'll tell you about how I'm scared, and we can be scared together, but neither of us will be alone in it."

And that is the most important thing, that you don't have to be alone with what you're feeling. Your partner doesn't have to be alone. Does that mean your partner should be your only confidant for everything you're going through? No, absolutely not. This is where you really do need that network of support, friends, family, other people who can really hear you and listen to you and not dismiss your feelings or tell you everything's going to be okay but really let you share what it's really like. That's very important.

But sometimes, letting the brave face drop and letting your partner know, "I would be so scared if I lost you. I would be so heartbroken if I lost you. That idea terrifies me. Let's do everything we can to make sure that's not going to happen." Your partner actually needs to hear that from you, and it will be a great relief because if you are not carrying some of these big feelings all by yourself and your partner isn't either, then you're together like the monkeys that are holding each other as opposed to separate on your own little individual islands the way there was in that earlier picture I showed.

So I know that some of this may seem, I don't know, unusual or perhaps surprising about what I'm recommending for how to really maintain the strong connection, emotional connection, and safety and security with your partner. But I'm really open to... We can stop sharing, and I'm really open to any comments, reactions, questions about what I've shared so far that anyone would like to share.

Sharon Levine:

Okay, so I have a few questions that have come through. The first one is, "What if the cancer patient just wants to be left alone and feels that she has no obligation to try to connect emotionally with her caregiver or family, that it's a one-way street while she is in pain and in active treatment?"

Dr. Lisa Blum:

Remember the slide that I showed with some people turn up emotion when they're dealing with some really upsetting things, and some people turn down emotion. So I would say that that's a person who is coping with intense distress and probably fear and pain and loss and grief by trying to turn down emotion by trying to distance and cut off and be separate.

And it's not that we can make somebody change their strategy, but what a... if the partner... I guess implied in that question is that maybe the partner is feeling kind of cut off. Maybe the partner feels like, "I can't even access my person anymore because she's so kind of in her own silo trying to deal with this." That's something that could be talked about gently, sensitively, delicately.

But I think it's possible to go to that person and say, "Hey, I'm really missing you, and I understand that you need a lot of alone time and a lot of alone space to cope with this, but I want us, and our relationship to stay strong through this. And if you totally go away from me, I miss you. I'm separated from you, and that's really hard for me. So could we talk about this?"

Sharon Levine:

Thank you. All right. Another question is, "How do you regain a connection with your partner in the aftermath of a cancer treatment when they've spent the last few years simply trying to survive?"

Dr. Lisa Blum:

Yeah, it's going to be slow, and it's going to be gradual. What's really important, and I kind of cover this in the next section about communication, is actually being able to talk about that, being able to name that with each other to say, "Hey, we've been through a hell of a slog for the last X number of years, and we've each maybe had to go into our own corners to try to cope and survive with this, but you really matter to me, and this relationship really matters to me.

And so I want to figure out how we can each start coming out of our corners. Are you willing to work on that with me?" It really starts with being able to name what's happening and make a plan to address it. And maybe that starts with really low-demand kind of activities like, "Could we start taking a 10-minute, 15-minute walk together every day, and we just chat about what we can chat about?

Can we think about something we want to do together, like maybe a small trip we could take together? Do we want to think about getting professional help and having somebody really guide us back into connection? But how do we actually make a plan for this?" Because if neglected, it likely won't happen by itself, but if it's actively addressed, it can.

Sharon Levine:

So, I'll ask one more question before we move on to the next section. "What if I begin to feel overwhelmed in my caregiver role?"

Dr. Lisa Blum:

That's a great question, and it kind of leads into... I might actually just jump right now to some practical strategies about caregiver needs. Maybe I could do that because this will really be an answer to that question. Is that all right? Okay.

I don't actually need the slides for this. I'm just going to speak. Mike referred to this about... this saying about put your own oxygen mask on first before helping the others around you. When you're in a cancer crisis or any kind of really serious crisis with threatened loss of a partner, that's actually really, really hard to do. Why? Because your focus and your own survival is so focused on your partner being okay so that you can be okay and don't experience this tremendous impactful loss, that it's easy for a lot of the direction and focus to go toward the partner. And it's easy to forget to put on your own oxygen mask first.

It's a really good recommendation, and I highly endorse it, but I'm just saying it's hard to do. So the question is, how do you balance the very real caregiving demands that are on you with also the need for some time off from being a caregiver and time for self-care and time for social connection? How do you do that? Well, the thing is that you have to ask for help. And this goes back to the thing that I was just saying about how, in our society, it's a rather hard thing to do to ask for help. We're supposed to be sort of these superhero caretakers who can do it all and manage it all, but the truth is we can't.

And this... And if you're able to really accept that and embrace that, like, "I'm going to ask for help everywhere I can because the situation is that hard," that would be a really good place to start. And so Mike gave some examples of what some of their friends and family and loved ones did. I want to just share a few more. A lot of times people say to me, "I've... About somebody else who's in crisis, "I've offered help. I've told them I'm around any time, but I don't know what they need. I don't know what to do for them."

Well, it's true that there's often this gap between what does the couple need or the family need when there's this crisis going on and what do you have to offer. One of the things that I have learned over time is it's really good for the caregiver to actually have a list of things that they need and to be able to, if somebody asks, say, "Great, thanks for asking. Here's number 16 on my list that I would love to ask you for." And also, that those of you who may be friends of caregivers or prior caregivers now tending to other caregivers, it's also really good for you to have a list of offerings and what could that include?

That could include things as simple as, "Will you curate a list for me of things that are on Netflix and Hulu that are really light and easy to watch and not too serious so that when at the end of the night we finally sit down together to watch something, we don't have to spend the first 20 minutes scrolling through Netflix trying to figure out what we should watch. Can you just make a list for me?" Or, "Could we have a standing date?" Kind of like Mike had with his friends where they came over before every Chemo treatment. "But could we have a standing date where you come by and pick me up and take me out to coffee for an hour?

Like a standing date. I don't have to call you. I don't have to arrange it. I don't have to go through the dread of asking you. You don't have to track me down. We just have a standing date." Or, "Can you come and take my kids out? My kids are spending too much time here huddled around their sick mom. Can you do something really nice for them? Can you take them away with your family on your weekend trip up to Big Bear and give us a chance to just stay in bed all weekend if that's what we need?" So really concrete ideas that you have generated in advance with your partner. Have a list. Have it in your phone.

And when somebody says, "Gee, if you need anything, I'd really like to help." Say, "Do you mean it because I have number 42 on this list." That is a good way that you can get some time off of your caregiving needs. Another thing that's really important is that you have time. You, the caregiver, have time to process your own feelings of guilt and anger and resentment and grief and anything else that may be coming up there. You cannot just be a robot who just keeps going and has to absorb and absorb and absorb and be there for your partner and not have a place where you get to unload everything that's going on for you.

This may be a little bit of a quirky example that I want to share, but I had a close friend who went through cancer. I'm glad to say she went through it. She is well. She is... She has no cancer now, but it was a very... a very rough two years. Her partner happens to be a musician, writer, performer, and he wrote a play afterward about his experience of being the caregiver going through this whole process. And one of the songs was, Don't Bring Me Any More Soup.

And it was a testament to his anger at the way that people, good intentioned people who wanted to help, but everybody wanted to make soup, and they had so much soup that they had no room in their freezer and no place to put it, and then they felt guilty because they couldn't accept the soup from the other people, right. This is an example of something that only a caregiver would know. Like, "I don't want any more soup," but a caregiver needs a place to be able to unload that.

You need a place to call up your best friend, brother, sister and uncle, pastor, therapist, somebody and you need to be able to say, "If somebody makes me one more freaking pot of soup, I'm going to throw it at them." You need to be able to vent what it is uniquely like to be the caregiver and to not have to worry about how that lands on anybody else because you would seem ungrateful or you would seem too angry or any of that. And when you feel angry at your partner because your partner didn't get out of bed for four days, you need to be able to tell somebody how hard that is.

You need to be able to vent, and you need people who can really listen to you, really listen, not cheer you up, not fix it, not make problem-solving suggestions, but just listen and hear you. And sometimes you're lucky enough to have those people naturally in your life. Sometimes, you may have to really seek them out with a Sharsheret counselor or with a professional therapist or with a chaplain, but you need to be able to vent. I want to just share one last thing about caregiver needs, and then we can pause again, Sharon, for more question.

Mike, you talked about having your own sort of happy place that you could go to keep you steady during such a difficult time, and that's incredibly important. It is sometimes very, very hard for people to find that if you're also the breadwinner and the main parent and the main shopper and cleaner and cook and all of that, it's sometimes very hard to find your really positive, healthy outlet for this. Of course, if you can, that's the best.

Sometimes, what people resort to are the other things that are available to them in the short and fast things like too much eating or smoking or drinking or too much online shopping, which are the more obvious ones or the less obvious ones, like too much Instagramming or too much TikToking or too much doing things that don't necessarily really make you feel better, like obsessive cleaning or reworking your calendar.

So the last tip that I want to say to caregivers is to really spend some time thinking about, "What are my coping strategies? What are my escape hatches, and how can I make sure that I'm choosing and moving toward the ones that are actually really restorative and affirming and good for me and healthy as opposed to the ones that really sneak in that aren't so good but that we use because they're available and they're quick and we have access to them easily."

So just kind of really doing a check on coping strategies, and if you need some new ones, get a friend to help you with that. "I need you to meet me for a 15-minute walk every morning because, otherwise, I'm not moving my body. Can you do that?" So really asking for the help where you need it, even with those coping strategies. Let me pause there again and see Sharon if you have some more questions.

Sharon Levine:

Yes. "What do I do if I want to talk to friends and family about the diagnosis, but my wife doesn't want me sharing any details."

Dr. Lisa Blum:

So I think one of the things that's really important, and actually, I'll just sort of weave in the things I wanted to say about communication here are that, during times of crisis, in order to feel connected and in order to feel like we can turn toward each other, we need more communication and not less. So that doesn't mean ignoring like, say, your partner's wishes to not have a lot of details exposed to other family members. That has to be taken into consideration.

But so does the need for, say, the caregiver to be able to let people know what's going on because it's very isolating. Think of those people all standing on their own little islands in the middle of the water. It is very, very isolating when we can't turn toward others to let them know what we're experiencing. So I would say that a big conversation might be needed for that question, Sharon, where the partner who's got the cancer can say, "Look, I don't feel comfortable for X, Y, and Z reasons with people knowing a lot about my diagnosis or my treatment or what the side effects are."

And maybe could define what they would allow... feel okay about people knowing and what they really wouldn't want people to know. Make some differentiation there. The caregiver also needs to be able to say, "I need to be able to talk to people and I am willing to talk to people within certain limits of what you are comfortable with me sharing, but I need to be able to share. So let's figure out where that middle zone is where we can meet and we can still be each getting some of our needs met."

Sharon Levine:

Another communications question. "How do I tell my husband that his disease has become the focus of our life and that I'm resentful about this?"

Dr. Lisa Blum:

So I just want to make sure here. So the person speaking is saying the husband is the one with the illness, and-

Sharon Levine:

Yes, [inaudible 00:59:45].

Dr. Lisa Blum:

... the wife is saying, "This has become the focus of our life?"

Sharon Levine:

Yes.

Dr. Lisa Blum:

Okay, so here's what I'm really talking about communication. If that's what you're feeling, that's what needs to be said. There isn't as much tiptoeing around... Or let me say that a different way. Tiptoeing around these big things isn't actually helpful. Speaking about them directly is much more helpful, even if those conversations are going to be hard because being able to turn toward each other with what your experience really is is what keeps that relationship feeling secure and connected.

So you may need a friend's help to figure out how you want to say it in a way that is kind and not sharp or mean in a way that is gentle. But if you are speaking from your own perspective, I think lots of us have heard about I statements, like say I rather than you. So, if you are to say, "I am feeling overwhelmed by how much illness has become the focus of all aspects of our life, and I need to be able to talk to you about creating pockets of something else. Pockets where you and I can do and talk about and be with something else, pockets where I can do that with friends, pockets where we can do that with our kids.

I need your help, beloved husband, to figure out how we can put a stake in the ground that is things that are non-illness related so that we can still stay connected and have outlets together." It's important to say what you need as a partner. That was sort of part of my original... As a caregiver, that was part of my original piece, that to feel connected to your partner, if you can't bring your needs forward, the relationship is going to suffer. So being able to express what you need too is critically important.

Sharon Levine:

There's a comment in the chat box in response to what you just said from a patient's perspective. "As a patient, it would be horrible to hear that my illness has been the focus." Do you want to address that?

Dr. Lisa Blum:

I could well understand that it might be really hard to hear that, but I think it would merit a conversation about whether it felt true because perhaps it feels true for the patient as well. And for the partner coming forward, not in blame... Let me say, the caregiver coming forward, not in blame or not in accusation, but in saying, "Hey, I think we may both be suffering as a result of this having taken over all the parts in our lives.

And while it's very big and it's going to live in a lot of our life right now, let's see if you and I together can craft a little safe zone where it doesn't have to exist. Maybe we start a tiny windowsill garden or something where it starts, and it's not about cancer, but let's do that together so that we are staying connected and we don't let ourselves be drowned by the cancer."

It may be hard to hear that, but it also may be a really loving thing that the caregiver is coming forward to say, "If that's true, then it needs to be adjusted," and that's out of love and concern and connection. So I would say it could... these could be hard conversations, but honest conversations are what's needed.

Sharon Levine:

Do you want to move on to the next section?

Dr. Lisa Blum:

Sure. Yes. I think there... Sorry, I'm just checking what I want to say. I think I'll move on at this point to talking a little bit about the sexual relationship because I know we're coming to the time that we want to wrap up.

So let me say just a few things about that. When there is a cancer diagnosis and perhaps surgeries and procedures and tremendous body changes and all of that, it is very normal and very, very natural and valid that there would be a sense of loss around the changes or the loss of your sexual relationship and fears that it could be lost permanently.

That would be very normal for both partners to be concerned with. However, sometimes, the caregiver partner, in particular, can feel guilty or ashamed or uncomfortable for thinking about that. "How can I be thinking about sex when my wife, let's say, is going through what she's going through, and it's horrible? How can I be thinking about sex?"

Well, I want to say that it's really important to be compassionate yourself around this because if you remember that slide that I showed early on where there was the balance beam, and then there were three important elements of relationships for both people, and those elements were our connection and our attachment are caregiving and sex.

Sex is a critically important part of an adult love relationship. And so if you are thinking about it, if you are mourning, if you're worrying about the future, that is really okay because it's a critical part of being in an adult love relationship, and you're allowed to be scared about it.

It's also really normal at these times for the person going through cancer to feel really insecure in the caregiver's presence about their body and how they look and whether they're ever going to be desirable again. The fears that can come... Sorry, the fears that come up around the loss of sex can really be about fear... can really be fears about being loved. "If I'm not desirable, will I still be loved?"

So these aren't insignificant fears or feelings, and when the sexual relationship is threatened, it can feel like the whole relationship security is threatened. I'll give you a really quick example of this. I was working with a woman who was going through pretty significant cancer treatment, chemo, radiation, the whole thing, lots of side effects, all of it. She was feeling pretty awful.

At this very inopportune time, her husband, who was quite a devoted caretaker to her, got a promotion for a very public service job, but a public-facing public service job. And as a result of his getting selected for this position, he had to do a lot of public appearances with people from various offices and government staff positions and all this. So he was, at the time, frequently in the paper and in the local news.

She lying at home in bed feeling terrible and watching all this attention to him with big groups of people and him at different various award ceremonies and presentations, and his arms around the teams of staff members that he was working with, got terribly, terribly scared and frightened that while she was in this awful position, he was out mixing and mingling with all these beautiful women and all these non-sick, very lovely people, and she was sure that it was going to mean an affair for him.

Now, in truth, there was no affair, and that was not in danger, and he was not with any of these people. He was just performing his public responsibilities. But she was terrified. And as you all know, sometimes, once you get on a particular fear, when you're in a vulnerable spot, that fear can spiral, man, and take you right down the well. They needed to talk about it. She needed to be able to say to him, "I am so scared lying here in this bed, in this body that doesn't even feel like mine anymore, and you're out there in the world with all these beautiful people.

I'm so scared that you are going to be drawn to them and away from me." She needed to be able to tell him. It was terrifying for her to tell him. And she felt shame like she was too needy or weak. Again, that theme comes up. But when she told him, and he was able to understand what she was experiencing, then he could be reassuring and turn back to her with a lot of care and love and reassurances. And each time he would go out after that, he would text her little love notes. "I love you. I'm coming home to you. I'll be home soon. You are my person."

That was how they rebalanced the relationship. But only if she can speak her worries and her fears and let him know what is needed. So really being able to communicate about the hard stuff, these hard conversations, and being able to talk about and name the changes that are taking place in your sexual relationship, in your sexual desire, in your feelings is really important. Being able to name it together puts you on the same team about it. It doesn't leave you each on your own little island standing alone with your fears and worries. Puts you together.

And one of the really important things that you can do is to talk about what you look forward to when this crisis is over when the treatment is over, when your body is feeling well and healed again, "What can we get back to? What can we hold alive and keep precious in our hearts and in our minds and in our fantasies that we know we can come back to together?" It helps to even watch a very loving or sexy movie together.

It helps to write stories about what you hope can return and resume and imagine together what can be restored when the time is right, when you're both feeling ready for that. And I want to say just one last piece, and then I will be wrapping up, Sharon. I'm on my final moment here, that even when you're in this place where sex just seems off the table, don't think about it as one monolithic thing. So maybe intercourse is off the table because your body just can't handle that right now.

But what could still be on the table? Could there be lots of extra kissing and holding and hugging and caressing and cuddling? Could there be even massaging parts of the body that don't hurt? Could there be erotic, non-sexual stroking or caressing? Can you play around a little like maybe you did when each of you were teenagers, whether that was together or not, but can you do first base or second base even if you're not feeling ready to make the whole commitment toward intercourse?

These kinds of ways of just keeping touch alive between you is very important. Even if you can't imagine being sexual right now, because these are ways that we show love and these are precursors to sex and they are ways that we feel cared for and comforted and connected, and that's the most important thing. So I'm going to pause there. I'm done with the part I need to say and I'm open to any additional questions.

Sharon Levine:

I'll give it one minute. I have one question that came in. "How can one approach or be understanding of a partner who has had a mastectomy when they are intimate?"

Dr. Lisa Blum:

That's such a good question. How about asking your partner? How about saying, "I want to be really sensitive to you and how your body feels if we're going to be close and connected, and I have no idea what it feels like to have a mastectomy. So can you talk to me about it?

Can you tell me where you do want to be touched and where you don't want to be touched? Can you tell me what kind of touch feels okay? What doesn't? Because I need to relearn your body, and probably you, my love, need to relearn your body too. So let's do this together."

Sharon Levine:

Okay. Thank you so much. Does anyone want to add another question to the chat?

Dr. Lisa Blum:

Sorry, Sharon, I think you got muted.

Sharon Levine:

Thank you. I want to thank Mike Kanarick and Dr. Blum. Thank you so much for educating us this evening for all of the tips and resources that you've both offered and that can be applied in our lives. And I know a lot of people might have some more questions. Please feel free to reach out. We can try and send them to Dr. Blum. I know that after hearing you speak and Mike speak, we're all more knowledgeable after hearing your presentation, so thank you so much.

Please take a moment to fill out a brief evaluation survey that is linked in the chat box now. Evaluations really do inform future programming, so thank you so much for that. We'd love for you to stay connected with Sharsheret via social media, where we post about events like these, program updates, and various ways to get involved. Thanks again to our sponsors for today's webinar.

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All are free, completely private, one-on-one, and our number is going to be in the chat box. You can also email us at clinicalstaff@sharsheret.org. Our social workers and genetic counselors are available to each of you. You are our priority, so please never hesitate to reach out. And thank you again so much.