

**Cancer Support for Single Women:  
A Discussion with Sari Ticker, PsyD and a  
Sharsheret Peer Supporter**

National Webinar Transcript

August 24, 2020

Presented by:



**This webinar was made possible with the support of:**

The Siegmund and Edith Blumenthal Memorial Fund



Melissa Rosen:

Good morning, my name is Melissa Rosen and I serve as the Director of Training and Education for Sharsheret. I want to welcome you to today's webinar, which is "Cancer Support for Single Women." Before we begin, I have just a couple of housekeeping items to share. This webinar, we want you to know, is being recorded and we'll post it on Sharsheret's website along with the transcript. Only the presenters will be shown on the posted video. Still if you'd like to remain anonymous today, you can shut off your video or change your posted name. Instructions on how to do that have been posted in the chat. You may have noticed that all participants were muted upon entry. Please keep yourself muted throughout the call. We actually recommend that you keep your screen on speaker view. This will enable you to see the presentation clearly, you can find this option on the upper right hand corner of your screen.

Melissa Rosen:

I was so excited to see that we received many, many, many questions before today's webinar. And if you have additional questions now, as we go on, please include them or type them into the chat box, which you can access at the bottom of your screen, and we will do our very best to answer all questions. Any questions that don't get answered, you will hear from one of our team in the next few days with an answer. As a reminder, Sharsheret has been providing telehealth services to the breast and ovarian cancer communities for almost 20 years now. And although we could never have imagined the world as it is right now, through our services, we have been preparing for this moment to continue to be there for each and every one of you.

Melissa Rosen:

Among our many programs to help women and their families navigate different aspects of the cancer experience, I want to highlight two that may be of particular interest to those of you on today's webinar. One of the many wonderful programs that our clinical support team can connect you to, is our link program. If you are looking to connect with someone who's been there, we can find a peer support match for you. And as we look for a match, we take into account several things, including your exact diagnosis, your stage of life, your specific concerns, because we want to match you with someone who truly comprehends what you are dealing with. We also understand that for those of you who are living with advanced or metastatic cancer, your concerns may be different. Our Embrace group on Facebook is geared specifically to you and your needs. This group is a closed group moderated by one of our members of our clinical team.

Melissa Rosen:

And you can become a member of this group by answering a couple of simple questions, and we're going to post a link to that in the chat box right there. It'll bring you to our website, and then you answer a couple of simple questions and the person who moderates that group will admit you. I also want to make you aware of our Spungen Foundation Family Focus Program Kit. This program is to educate and support caregivers, all caregivers, not only including spouses, but siblings, parents, friends, adult children, and more. Those caring for you in person or from afar. If we can help them, then they can help you, and that's really the goal.

Melissa Rosen:

As we move into the webinar itself, I want to remind you that Sharsheret is a national not-for-profit cancer support and 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 a specific medical condition. You should not use this information to diagnose or treat a health problem, and always seek the advice of your physician or qualified health provider with any questions you may have regarding a medical condition. Okay, with that out of the way, let's get to it. We begin today's program with two survivors who have also served as peer supporters. They will share their stories and some of their hard earned knowledge. So, first I want to introduce you to Pam who will begin.

Pam:

Hi everyone. As you've heard, my name is Pam and I've been a breast cancer survivor for almost four years. And I say "almost," because every month is really important. You count every single month, and I'm very happy to be here. First, and I'm sorry I'm reading. First, I want to say that I've benefitted so much from Sharsheret, both through directly speaking to some of their social workers, and I was matched to a peer support person, I can't tell you how helpful was. We were strangers, but we became friends and she was always available to me. To give you some background on my cancer story, first, let me say, and I don't want to be depressing, but I'm going to tell you my point of view, it's terrifying. So if you feel terrified, it's true, it's terrifying. I was diagnosed initially with a single spot of DCIS and the doctor said, "I'm sure it's nothing." But it wasn't nothing. And so standing outside waiting to go into my eye doctor in the middle of Washington Heights, I got the phone call that, "It wasn't nothing, but I'm sure it's just one spot." And this was in July 2016.

Pam:

Two weeks later, I went to one... and I'm in New York City, I went to one cancer center to discuss having a lumpectomy. In the course of having an MRI before the lumpectomy, and I hate the word literally, but I literally was in the ultrasound room for four hours being scanned and re-scanned and people would disappear. And ultimately after the four hours, the radiologists came out and said, "You have DCIS all over, and you're going to need a mastectomy." So of course I was devastated. I couldn't even breathe. And then I went about a month later when I could get another appointment at a different cancer center, because I wanted to confirm that this was true because it was so unexpected. They confirmed the diagnosis and then I was followed up with a number of guided MRI biopsies.

Pam:

In September, Memorial Day weekend, I had a single mastectomy followed by expanders, and I wasn't really happy with what was going on with the expanders and how I was going to look afterwards. So after the expanders, at the beginning of 2017, I had an implant and about six months later I had a nipple graft, not a tattoo, a graft. Fortunately or unfortunately, I didn't need any more care after that. Just I take evista afterwards instead of tamoxifen and some of the other things. After that, I started alternating every six months an MRI, and then the other six months having a mammogram and an ultrasound. And I go every six months to just speak to an oncologist. And as I said, I'm almost four years clear. So now I'd like to share with you, and it might be one of the questions later on, what I've learned from this experience.

Pam:

And this is only my advice, only based on my own craziness and personality, but if it's going to help you, I'm happy. I have four tips. As a single person with family and friends who tried their best to be supportive, their help wasn't always so helpful to me. And I would recommend this book by Letty

Pogrebin, called How to Be a Friend to A Friend Who Has Cancer. It was so (oh, it [the title] was sick). Okay. Yeah. You really need to be your own advocate. And if this is not your personality, then it won't work for you. But I had to really counter what I've been taught growing up, doctors know best, this is the greatest cancer center in the world. You have to stand up for yourself when you have questions. When you have a doctor who kind of runs in the room, doesn't even sit down and then leaves, you've got to say, "I have some more questions."

Pam:

It's your life after all. You may not have something terrible, but it's certainly terrifying. I actually, and I don't think I mentioned this to Aimee or Becky, I met with one plastic surgeon who was going to do the reconstruction, a man. And he kept saying, "Well, this really is not a big deal. It's so straightforward. It's not a big deal." And I could feel my temper rising and the tears about to stream down my face, and even as I say it now, I get kind of upset. I said, "Well, maybe not for you, but it's a big deal for me. I'm a woman. I'm about to lose my breast. It is." And then I actually said, "I don't think this is going to work out. I don't feel comfortable." And again, that's not something I've been brought up to say. He's a good doctor, maybe it's not a big deal, but you really have to listen to yourself. Something doesn't feel right, unless you live in the most remote place in the world, there are other doctors.

Pam:

Now let's see, go with your instincts. Like I said, if something doesn't feel right... After I had the expanders, I had a bunch of side effects. I had a buildup of fluid and it looked like Dumbo's ears flapping around. And they kept telling me, "Oh, that's normal." And I asked everyone I knew who had gone through this and it wasn't. So I really had to fight to get seen and get it drained. So if it doesn't feel like something that is normal, even if they tell you it's normal, it's not. And so when I had the expander, and you get the saline injections to increase the expansion, I wasn't happy how it was going to look. So I said to the plastic surgeon, "Will this look any better afterwards?" And she said no. So with that, I said to myself, "I'm not happy with this." So I went to a private plastic surgeon, not affiliated with the hospital, and I was much more satisfied.

Pam:

Another thing, depending on your personality, if you feel like people, your family, your friends, your significant other, isn't really being helpful, and if you think you don't feel comfortable saying, "I need help", Sharsheret is wonderful. Even growing up, I don't know if you felt it, people would say, "She has cancer." People wouldn't say the word [whispering]: Cancer. And these days, it's not something you want to shout on the rooftops, but it's okay to say it. You never know who you're going to find who's had it, who knows someone, and anyone can help you. I didn't go to Mount Sinai, but I found a wonderful support group of people with pretty much my diagnosis at Mount Sinai, and they let me participate.

Pam:

Now, for some of the things, maybe this'll make you laugh or maybe it will feel a bit better with what people said to me. "Don't worry, you'll be fine." All the time. "Don't worry, you'll be fine." They meant well, but when you're terrified and you want to be reassured, it's not always the most helpful thing. "You're so lucky to have stage zero. So lucky." Well, you're not really so lucky. What would we better? Not having it? I have a friend who said, "I had a friend who had a double mastectomy. She didn't have implants and she is so happy with her life. She's got these tiny little breasts and she's thrilled." Well,

you're terrified. You need someone to, at least for me to validate, "Yeah, I understand you're scared. It's scary." My social worker at my doctor's office called me and I was stepping into Trader Joe's and she said, "We don't think you're coping very well."

Pam:

I just said, "Well, thank you and I'm doing the best I can. Have you gone through this?" And then another person said to me, "Well, what's your prognosis?" I said, "Well, I hope I'm okay." What are you going to say? So to whatever extent you feel comfortable, reach out to others because so many people have gone through it and it's not a taboo anymore. You only tell people who are appropriate, you feel comfortable with, but you'll be surprised how many people know someone related to someone and they're all willing to talk to you. So don't go through this alone because it's just too hard. It really is, especially now during a pandemic. So I don't want to depress you through my experiences, but I wanted to re reassure you that this is very hard and although you may not think it now, you're going to get through it. Just take it one day at a time.

Melissa Rosen:

And thank you so much.

Pam:

You're welcome.

Melissa Rosen:

That is great advice. One day at a time and it is hard, but that doesn't mean that it's impossible.

Pam:

No, you'll get through it.

Melissa Rosen:

Absolutely. I'm sure people will have a lot of questions. Right now though, I want to move and introduce Shana, who is also a survivor and a peer supporter. And she's going to share a bit of her story. Shana. Shana needs to be unmuted.

Shana:

Hello. Thank you for doing that. So I was 25 and I felt something under my arm in the shower. And I have a very close friend who's an OB-GYN and I called her and I said, "I feel something and I don't know what this is." For me, it started with a whole bunch of appointments and tests that were inconclusive because people were looking at me and saying, "She's 25. What in the world?" And on the other hand, they weren't sure what they were looking at. So thank Gd, she pursued with me and after a couple of months she said to me, "There just aren't enough answers." And she sent me to a surgeon and the surgeon I found was actually like right across the street from where I worked.

Shana:

And I went by myself and I sat there for, I think, three and a half hours, and then finally I saw this surgeon, and she didn't need a biopsy. Within really a couple of minutes, she walks in into the room with a really nervous looking nurse. And I looked at her and I was like, "So is it something bad?" And

she's like, "Yes." And I think she walked out at that point. The nurse then started giving me a whole speech about all the things that I needed to do and all these different pieces. And I don't really remember hearing any of it. Finally she said to me, "Is there somebody I could call?" And my parents were actually overseas. So I said, "I have a really close colleague, she's literally across the street." So we called her and I went to see her. I think I just ran across the street and she said to me, she goes, "Are you okay?" And I said to her, "I think I was just diagnosed with cancer."

Shana:

And of course at that moment, my parents called knowing I had this appointment, and from 6,000 miles away I had to share this crazy, crazy situation with them. And that's what started, the initial few days are filled with a thousand questions and so few answers, and that's very hard. They do test after test and they try to figure out what's going on and it's just confusing. One of the things that sticks out for me, as I remember in those initial few days, I was meeting with the radiologist who was trying to interpret some scans. And she looked at me and she goes, "Someone told you you're going to be okay, right?" And I'm like, "Not so far." They forgot that little piece. And she goes, "It's going to be hard, but you're going to be okay." And I think that was the first time I heard that which I really appreciated.

Shana:

It's just a lot of hard decisions, a lot of pieces. I was obsessed with keeping it quiet. I couldn't handle any of it at that moment. I didn't want to say the word out loud, I didn't have anybody that I felt could really get it. So I really spent a lot of my energy keeping it quiet which I think was a huge mistake. My family, my parents, my siblings were my gatekeeper. They protected me. They took me to appointments. They were there. They were the people in my life. I allowed a couple of friends in, but to be honest, when you're 25, they didn't get it. They didn't get what I was going through. They didn't get the stress. They just didn't have the experience of the life experience at that moment, or I didn't let them show me that they had the experience at that moment to be really supportive for me. So, I'd walk into an appointment with my mom and the person would start handing her all the paperwork and asking her questions and I'd be like, "No, no, no, it's for me." And they were just confused and looked really embarrassed.

Shana:

That part was hard about being young and being alone, so to speak. It took me time to find the right medical team which was a really important piece. Pam talked a little bit about that. Finding the people, it's not only about how many degrees they have or how many procedures they've done, it's really who's right for you, and who's looking at your needs and addressing your needs? I met with an oncologist who I asked about fertility and he's like, "Well, 50% of couples are infertile anyway, so just give up that dream." And I looked at him and I was like, "Oh my Gd." And I think it was the first time I actually walked out. I literally walked out. Number one, that's ridiculous. And number two, don't bring your negative energy into my world right now.

Shana:

I needed people that were positive. I wasn't looking for guarantees. I don't do that. I wasn't looking for someone to sign a piece of paper saying, "This will happen for you." I was looking for somebody who shared my understanding and my life view of what I was trying to fact-find and just figure out. I needed somebody with that positive energy. And I found that eventually, but it was a hard process, and it was very lonely. And then Sharsheret comes in. I wasn't strong enough at that point to make the first phone call. My mom made the first phone call. But that opened an entire universe of support and

understanding that I have had on an ongoing basis for 15 years, literally. With different people at different points, I had different needs. That was a very cool thing. Sharsheret has followed me through all of my life events and experiences.

Shana:

We laughed together, we cried together, we danced at my wedding together. I send pictures of my family and that's really incredibly special. And I'll tell you that when my own mother was diagnosed with breast cancer, 12 or 13 years after I was, they were there for me then as well. So it's an amazing resource that is just opened up friends and people who feel like family, really people are a part of my family, and it's a huge deal. There are a lot of times when I really struggled. The time that was one of the hardest for me was when I had to be a normal person again, after all the surgeries and all the chemotherapy and all of the pieces, that they look at you and they're like, "Okay, you're good. Now go live life again."

Shana:

And that was a really rough time for me, a lot of therapy, a lot of support, really a lot of just different parts to the journey. And at that point things started getting better and getting more stable. I started dating, I eventually got married. I have three spectacular little girls who are the permanent reminder for me that my life is one big giant miracle. And also, one of the things that I've really changed about how I look at life and some of the unexpected pieces is the appreciation of the tiny, small things, which aren't so tiny and small. The regular things that I get to experience after having been through this, the actual smelling of roses and like today where I took my oldest child to kindergarten for her first day of school, such a regular and normal thing that I really treasure. So thank you.

Melissa Rosen:

Thank you so much, Shana. Thank you both so much for paying it forward to help others and for sharing your personal experiences. I know as a survivor myself, that it is so helpful to hear from people who have been through what you've gone through, what you're going through. Our next presenter has a wealth of knowledge in a critically important field. Dr. Sari Ticker is a Licensed Clinical Psychologist at Illness Navigation Resources who provides individual therapy and consultation for adults and couples. In addition to her psycho oncology experience, she has experience in treating depression, anxiety, grief, loss, life transitions, and adjustments in physically healthy populations and patients and families confronted with a medical diagnosis. Dr. Ticker also offers caregiver supportive resources when there is an acute or chronic medical condition in the family. She's also an active volunteer with local and national organizations that educate and support communities facing the emotional impact of medical illness. Of special note, participates in the Health Education Taskforce at the Sarnoff Center for Jewish Genetics, which is a longstanding Sharsheret community partner. There she helps to promote awareness of hereditary cancer to communities across the country. Thank you.

Dr. Sari Ticker:

All right. Thank you. Can everybody see the presentation okay?

Melissa Rosen:

Yes.

Dr. Sari Ticker:

Yes, okay, all right. So hi everyone, and thank you again to Sharsheret for putting on today's webinar. Again, I'm Dr. Sari Ticker, and I'm a clinical psychologist in Chicago, and my work focuses on the emotional impact of a cancer diagnosis. I know from my own clients and also seeing the number of people attending today, that this is such a common issue, and I hope that our discussion really helps to provide some insight and tools regarding the support. I do want to preface a few things before we start. First, I recognize 10 to 15 minutes is not enough time to cover all of the topics in depth. So we will have the Q & A after, and I'll also provide my email for those who have any other questions after today. And the second is that everything I'll go over is meant to be recommendations and suggestions. At the end of the day, it really is personal preference, so please feel free to pick and choose the aspects that work best for you.

Dr. Sari Ticker:

So to start, let's take a look at social psychology. Our core and social psychology really teaches us that we desire to connect with others. We live in communities, we work in groups, we may worship together, we play on sports teams, we may participate in different clubs. So it is completely normal, completely expected to crave support from others. We are hardwired that way, and we may differ in terms of what those specific needs are. When we talk about support, they really fall under these three main umbrellas that we'll touch on today. The first being logistical: so organizational, appointments, set up, day to day things. Medical support, that's refrained more so to what the medical team is providing treatment and care, and then emotional support which is my area of expertise. Having someone to talk to, having someone to give you a hug, having someone to create a safe space for you to experience whatever emotions you have.

Dr. Sari Ticker:

I will also note that there is research that suggests that support from loved ones can help contribute to better outcomes with cancer. So we know as academics and we know as patients and families, that this is a really big deal. And so for the purpose of our discussion today, a lot of the slides will focus on that emotional component. So I included this image that I use with my clients. It is a distress thermometer, and hopefully you can see it on the screen okay. But I find this can be particularly helpful when someone is feeling overwhelmed. Where do I start? What do I address first? And so beside the thermometer, there are different areas where a patient can highlight or circle the needs or concerns that relate to them, and then also rate it on a scale from zero to 10, 10 being the most distressful.

Dr. Sari Ticker:

So after going through the list, it can really help provide that visual and to prioritize what do I need to address first? So if you can't see already, some of the categories include financial, emotional, nutritional, spiritual, and I will also note that needs will change over time. So it would be helpful to revisit this at different points in your cancer journey.

Dr. Sari Ticker:

So what do I mean by that, that needs may change? Well, support not only looks different for each person, but it'll also depend on what point you are in. So I listed a few common trends that I see in my work depending on the different stage or point in a cancer journey. To start, those who are newly diagnosed, there's loss of control, loss of structure, there's shock, unpredictability. And so support may look like having a space or someone who can provide a safe space for that emotional unload. Patients



who are in treatment, a lot of the support revolves around logistical. Thinking about physical strain and issues related to treatment, help with daily tasks, checking in with the patient and emphasizing not necessarily expecting a response, but just checking in to show that you're there and available.

Dr. Sari Ticker:

And then I also want to highlight post-treatment. This is definitely at the point in which I get most of my referrals. This is a point that for most patients, this is where the heaviest of the emotions fall. Not only does support from family and friends tend to dwindle at this point, there's an assumption that you're done treatment, you must be all better, we can move on. But also during treatment and from time of diagnosis, it's all about survival. And there's not really that space to process the emotions just yet. So this is a big time when we're talking about the need for emotional support. Also highlight those who are in chronic treatment, ongoing treatment, it is a marathon. So again, the needs may look different for those in chronic treatment.

Dr. Sari Ticker:

Even though we're not focusing on caregivers today, I do want to highlight that caregivers and loved ones are also in need of support. They are impacted by a diagnosis, they are part of the system. It is not up to the patient to be their support, but I want to highlight in case there are any caregivers on today that it is also expected in order for you to need your own support.

Dr. Sari Ticker:

How to identify our needs? I think this was brought up already, but it is so important to ask for very specific needs. The more specific, the better. Whether it's to provide a meal on a certain day, to run a particular errand, to go for a walk. Loved ones typically want to help but don't really know how, so may say things like, "I'm here if you need me. Call me if there's something I can do." But I do recognize that it can be hard to ask for help. Some of my clients say that challenge is because they are used to being the caretaker for others, or they feel like they may be a burden on their support circle. You are not a burden. This is not a time where there's expected reciprocal interaction. Please use those who are around you. They are there to help you.

Dr. Sari Ticker:

It can be helpful to also seek outside support. Counseling can be a great supplement to your friends and family because your therapist or psychologist is not going through it the same way that your family or friends are. It can also be extremely helpful to have a healthcare proxy, someone who helps to take charge to participate in appointments, even if it's by phone, someone who can help with medications, ask questions to doctors, et cetera. And lastly, I will emphasize, please, please, please utilize your hospital social worker. They are not only there for social support, but they can also help connect you to resources in your community. So I'll talk about some resources at the end of my presentation, but the social workers are great for local resources as well.

Dr. Sari Ticker:

Cancer is a time when the predictability really goes out the window. It's very scary to live in a time of uncertainty, so here are some ways that a patient can be proactive and times when we can anticipate an emotional reaction. And I say that vaguely because the reactions can differ, whether it's by the emotion or intensity. So first treatment: Unpredictability at its height. What does it feel like? Will this hurt? Will I get sick? Support may look like having someone you trust to pick you up or having meals set up, having

somebody come by or check in with you. Scanxiety is the anxiety, the anticipatory anxiety that a patient may feel as they are approaching a routine scan as a follow-up, or a scan to see how treatment is working. We tend to see this uptick in anxiety and ideally the anxiety drops off after receiving clear scans. So think about what would be helpful for you to feel supported, not just after that appointment, but the lead up to it.

Dr. Sari Ticker:

Lastly, change is very scary, and especially when there's changes to the treatment plan. So it really highlights that there is so much uncertainty. There is nothing that is 100% guaranteed, so we can also expect this emotional uptick at that time. And I say this to help provide normalization if that happens for you. So when it comes to your medical team, I've listed here some different ways that you can get the most out of your relationship with your doctors and healthcare team. I won't go through it bullet by bullet, but overall it comes down to organizing everything in one place, and writing things down. Those are the key themes. There's a lot going on and it's very hard to remember all the aspects. So the more support that you can have with other loved ones in the appointment, even if it's on speaker phone, that is always helpful.

Dr. Sari Ticker:

Emergency planning, hopefully something you never have to use, but always helpful to have something in place should an emergency come up. So that could be as big as who are my doctors? What are my medications? To something like who is going to water my plants? Who is going to walk my dog? Really covering the whole gamut. It's also recommended to talk with your doctor about who you should contact when questions come up, big or small, during office hours, as well as after office hours. And lastly, what can you expect from your treatment, from your first treatment? Just to help with that anxiety throughout the course of treatment.

Dr. Sari Ticker:

I know we're short on time, so I won't go through this slide in its entirety, but I wanted to highlight that there's what we call some problematic personalities that you may experience in those around you, again, maybe really well-intentioned, but are not helpful. So the Nosy Nellies, the friends who want to give advice or tell stories, or on the other end of the spectrum, perhaps friends or family members who are silent. And so I show that to give some normalization that these are really common things that I will see in my work, and trying to navigate some of those relationships can be very tricky while you have all the other medical things on your plate.

Dr. Sari Ticker:

I could probably do a whole hour on this topic. So just to touch on it briefly, when it comes to dating and intimacy, it is a highly individual thing. It's very different person to person, but I did want to go over some general things to think about. The first is that you need to be comfortable with yourself. It's so hard to invest in any kind of relationship, especially a romantic one if you're not comfortable with yourself. So that may take some work in therapy or just some reflection. When it comes to sharing in a new relationship about the cancer or about the history of cancer, it can be helpful to practice what you're going to say, to pick a low stress or non-rushed time to talk about it. And also to talk with your healthcare team about some potential sexual side effects. How will this impact your romantic relationships and dating?

Dr. Sari Ticker:

And then lastly, I also wanted to highlight Sharsheret's BFF program, which there's more information on the website, but Sharsheret can include kits that have makeup and skincare products and eyebrow stencils, and also has services and subsidies for eligible individuals for some of those nonmedical services to help improve quality of life and body image. So something definitely to take a look into. A few helpful reminders: The one that I emphasize the most in session...

Melissa Rosen:

I think Sari froze for a second. Sari, can you hear us? Okay. I think what we should do, and this is always the problem with Zoom, and they actually had an international blackout earlier today. We're lucky it worked when we started. Until Sari comes back, let's start answering some of the questions that came in beforehand for Shana and Pam. And then as soon as Sari comes back, we'll jump back to her, Dr. Ticker, and then we'll continue with questions when she's done. But some of the basic questions that came in, what's the most important tip you'd share to someone who's newly diagnosed? Shana, you want to start? And then Pam will get from you as well. You're muted.

Pam:

Okay.

Shana:

Okay. There we go. The most important tip, I think, is taking it moment by moment. And we all like to see a week, a month, a year down the road. You can't really do that. You just need to take one situation at a time, gather information, look at all the specifics, meet with your team, meet with your loved ones, make informed decisions, but it's really important to be in the moment and just see it as one step at a time. Because unfortunately, people can tell you, "This is what's going to happen. This is what's going to happen." Every person is different. You can hear from 10 people, you'll hear 10 stories. Everyone's journey with the medications are different with what their options are... Everything is just so different for each individual.

Shana:

Things that I had a really hard time with, some of my close friends had no issue with that whatsoever. So I think that though we all want the whole picture right away, it doesn't do us any favors. So it's really a kind of take one thing at a time. I remember one specific thing that really sticks in my mind is somebody said to me, "It's going to be a year of pure hell, and then it's going to be great and you're going to be fine." And I remember calling this person up after a year and I was still in chemo and I was still dealing with a million things. And I was like, "You said a year, and it's a year and you lied, you big fat liar." And I was so angry and obsessed with that year. It just wasn't helping me. And instead of just kind of taking it one step at a time.

Shana:

So I think though we all love... I like planning, I'm a control freak, admittedly, it's really a one step at a time kind of situation, and try to just kind of make good decisions one step at a time and not try to see the whole future.

Melissa Rosen:

Thank you. That's very helpful. Pam, do you have something brief to add?

Pam:

Sure. In addition to what Shana just said, I would also add that this is your time, so take care of yourself. Be good to yourself. If you don't want to do anything today, don't do anything today. Don't judge yourself. When the person said to me, "You're not coping well." "Oh my Gd, I'm not coping well? Bad you." Just take care of yourself, be good to yourself and don't worry what other people think of how you're going to react. So just be nice to yourself.

Melissa Rosen:

So Pam, let me ask you this then, knowing all you know now, all the information, almost four years out, is there anything you would have done differently?

Pam:

I think the main thing was that the place where I had my surgery in the beginning of my reconstruction didn't really feel like the right atmosphere for me. It was very cold, it was very clinical, it felt a little like a factory. And when I went to a second hospital with the support group and I saw all the psychosocial things that were offered there, in hindsight, I would have gone to a place that felt better for me. I went to the place that was, I mean, "Oh, it's the best place in the world." But programmatically-wise, it wasn't the right place for me. So go with your instincts.

Melissa Rosen:

Okay. That's great. Shana.

Shana:

I would have increased my circle of support, no question. I spent so much energy trying to keep things hidden that I forgot to let people in. I forgot that so many people loved me and just wanted to be there. I really would have let more people in and I think it would have been easier some of those early months of feeling so alone. I made a lot of assumptions about what people knew and didn't know, and how they could be helpful in their own life experience. I just shut the door on so many things that I think could have been helpful, and I know I'd do that differently now. So I definitely would have changed that.

Melissa Rosen:

Okay. Thank you. So I know that Dr. Ticker is trying to get back on. We're going to answer a couple more questions, but I'm going to go a little out of order because there are certain questions that... Oh, she's back. So we're going to actually stop the questions now, and go back to what Dr. Ticker was talking about, because actually a lot of her information is answering some of the questions we got ahead of time.

Dr. Sari Ticker:

Oh, sorry, everybody. That's what happens when we work from home. For sake of time, I won't share the screen, but I'll still go through the information that I have. So I think the beginning is what I was saying about cancer not being your only identity. You existed in the world without cancer, and you had interest and hobbies and activities. So don't forget about those, spend time doing things that really make you feel like you. I also want to emphasize that everything is temporary. Temporary may mean

different things, but everything is temporary and things will change. So this can be a very helpful reminder when you are feeling at your worst or just really having a hard day. That is a good mantra.

Dr. Sari Ticker:

I will also share that avoidance is helpful until it is not. So I am guilty, I think we are all guilty of using avoidance. We use it because it works, but we do hit a wall where it doesn't work. And so it's important to have other tools in your toolbox and therapy can be a great place to examine that. And also setting realistic expectations, so let's not expect we're going to be playing a whole round of golf right after we finish chemo, it's important to really talk through with your doctor what you can anticipate at different points. I did want to highlight a few things quickly. I know our focus is not about COVID, but I know that there may be some questions. Ultimately I am not a medical doctor, always most important to check with your doctor and your health care team. They're your conductors. They are going to help decide what is best for your safety. And I recognize that physical support these days is more challenging.

Dr. Sari Ticker:

Check with your social worker, they may have some virtual services available. Social distance visits are great right now that we can take advantage of being outside. We can be creative. There's lots of interactive games we can access online. And I think also as we're approaching the holidays, you are always welcome to contact a local rabbi, a local synagogue and ask how you can participate in services for the upcoming holidays in a way that is safe for you. And then quickly for any caregivers on the call, I want to emphasize that it's about listening. It's not always about doing that silence is very loud, and not to force patients to see the silver lining. Sometimes the moment is not happy, it's not enjoyable, and that's okay. I think a lot of the times we force that because we're uncomfortable sitting there as the loved one.

Dr. Sari Ticker:

And then lastly recognize that medical decisions are ongoing. So the conversations may continue over time. I know we are short on time, so I am, if it's okay going to just pull up this one slide that had the resources on it so that everyone can take down the different resources available. CaringBridge is great. So you don't have to return a million calls and emails. You can post it on a private blog that only those who you send it to can read. Meal Train is a great way online to coordinate meals. Online forums are there. Imerman Angels, similar to what Sharsheret does with the peer mentor program is available. American Cancer Society has great resources both emotional and logistical. GoFundMe as well as professional support, and of course, Sharsheret. So thank you again. Sorry about that, everybody.

Melissa Rosen:

Thank you so much, Dr. Ticker. That was wonderful. And it's interesting how we have a list of questions that came in, and your presentation really did cover a great number of those questions. So I may ask you to speak a little more on a couple of things that people have expressed interest in. But one of the things that struck me as we talk as a group of people who have been through cancer, or who are going through cancer, we talk a lot about being isolated, about being immunocompromised, all these things that we've had to worry about. But now, as you started to mention, COVID, the entire world is worrying about as well. And in some ways that makes it easier for us, right? Because people are used to getting on Zoom calls and playing online games together, or sitting six feet apart in a front yard to talk. And in other ways it makes it more difficult because we still, in addition to the emotional support, many times need physical support, particularly during treatment.

Melissa Rosen:

So I'm wondering if you have any suggestions for those who are post-treatment, postsurgical and really need some physical support as well, and are living alone, what resources they may look into.

Dr. Sari Ticker:

Right. A lot of organizations at this time are doing virtual services for emotional support. I think this is a great time where the medical team can help strategize with you what that looks like. If there's someone close to you, who it would be safe to be close to, perhaps there's a way to go about that so that you can get that physical support. Again, like I mentioned in the summertime, or now that it's warm, if you get the okay from your medical team, it can be so refreshing to sit with a friend outside in a backyard or in a park and feel somewhat normal, and to focus on topics other than the cancer. I do think, like you said now, since everybody is kind of concerned about their health in a whole new way, and germs and how to stay healthy, this definitely can work in terms of empathy. So I think family and friends, if you share your concerns about maybe some of the precautions they're taking or not taking, then I think more so now than ever before, family and friends are more empathic to understand what's comfortable for you.

Melissa Rosen:

Thank you. Thank you. So one person asked when you don't want to bother others, but you're alone, how do you propel yourself to get that comfort? And I think that's a very insightful question. And I'd love to hear from each of you very briefly, Shana, Pam and Dr. Ticker. Shana, do you want to just start? Do you have any... And don't feel pressured to answer, but if you have something relevant we'd love for you to share.

Shana:

I think you kind of have to have in your head, it's almost like what you need when. It's almost like you take this medication for this and this medication for this. So for me, it was often my parents would recognize it before I would...If I was just totally losing it, and they were able to help me with that. So I had that kind of checks and balances. For somebody, it might be a best friend, for some people it might be a therapist who would say, "Okay, you don't sound good right now." So I think everyone has to have their person or their kind of red button that you push when something isn't quite doable or manageable.

Shana:

Sometimes you can't see it yourself, but if you have that person checking in with you regularly, again, it doesn't matter who it is, then you can realize that you really need to reach out. Or they are checking on you regularly, so they are recognizing something's not the same as it was yesterday. So I think it's kind of having kind of a plan, a preplan when you are feeling amazing. And you're just trying to put your support in place.

Melissa Rosen:

Thank you. That was very helpful. In the interest of time, I'm going to move to another question because I want to try and get as many in. The next question, and Pam if you could speak briefly to this, if appropriate, and if not, we'll ask Dr. Ticker as well. How have you handled disclosure to others? For example, when you meet someone new, possibly dating, when your needs change, maybe you need modifications for work, having someone you didn't tell initially, how has that worked for you?

Pam:

I guess I feel that it's the kind of thing that you share and you feel really comfortable with someone new. Unless they volunteer it themselves, having gone through it, I really like Dr. Ticker's different classifications of people, the Nosy Nelly and the prying people. I feel I hold back until I know someone well.

Melissa Rosen:

Dr. Ticker, do you have anything to add to that?

Dr. Sari Ticker:

Yeah. I think it's maybe helpful to have different scripts, the elevator speech and maybe something that has more details. And again, it's totally up to the patient to decide what's comfortable for them. Even if loved ones disagree, it's your personal information. And so I agree with Pam when you're comfortable, that is a good indicator that it's okay. But again, you can always choose not to disclose or not to disclose further, not to answer other questions and to protect your own privacy.

Melissa Rosen:

Thank you. So it is nearing the end of an hour. I want you to know that we are aware that many questions didn't get answered, questions about being a single mom and caring for children and talking to children, both younger and older. Questions about people living with metastatic disease. Questions about those who are in the LGBT community. We are going to work to answer all of those and email you those answers. The one note I want to end on is somebody did ask how can I feel more at ease with being single and accepting my diagnosis and recovering? And I just think it's important very quickly to point out that sometimes when we get a diagnosis of cancer, it can feel limiting. And if we are single, very often, we feel like we have so much in front of us. We can feel we have so much in front of us, and we're open to so many different, exciting options. So I just think it's appropriate to acknowledge that this may change the way we think about our lives.

Melissa Rosen:

I want to thank Pam and Shana for sharing their personal experiences. And thank you to Dr. Ticker for sharing her expertise. I also want to thank my amazing colleagues, Aimee Sax and Becky Koren, who worked with all of the speakers today to create this amazing presentation. I want to acknowledge our sponsors, the Florence and Laurence Spungen Family Foundation and The Siegmund and Edith Blumenthal Memorial Fund. Finally, an important reminder, Sharsheret is here for you and your loved ones during this time. Sharsheret provides emotional support, mental health counseling, and other programs designed to help you navigate through your cancer experience. All are free, completely private, one-on-one. Our number and our emails are going into the chat box right now.

Melissa Rosen:

Our social workers and genetic counselor are available to each of you. You are our priority. Your health, your wellbeing, we are all going to get through this together. I also want to let you know, we have several exciting webinars on a wide range of topics planned for the summer and the fall. This is the first time I've added the word fall, that's a little scary. Please check our website regularly to see what topics are coming up. We're going to post a link in the chat box again to find what's coming up, but I want to let you know the next two that are coming. Sunday the 30th, this Sunday, is the second of our three-part fitness series. Join us for Box + Align at 11:00 AM Eastern. Registration can be found on our website.

Melissa Rosen:

And then a week from today, the 31st at 2:00 PM Eastern, Sharsheret is going to host the second in this relationship series, Navigating Partner Relationships During Crisis. If you know someone who might benefit or be interested, please let them know they can learn more on our website. I want to thank you guys for joining us today. And please note, we'll be in touch to answer questions and you'll be getting an evaluation. Take two minutes to fill it out. It really does impact our future programming. Thank you.

Aimee Sax:

And actually the evaluation link is in the chat. So if you'd like to fill it out today...



## About Sharsheret

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

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

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

Sharsheret offers the following national programs:

### The Link Program

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

### Education and Outreach Programs

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

## Disclaimer

The information contained in this document is presented in summary form only and is intended to provide broad understanding and knowledge of the topics. The information should not be considered complete and should not be used in place of a visit, call, consultation, or advice of your physician or other health care Professional. The document does not recommend the selfmanagement of health problems. Should you have any health care related questions, please call or see your physician or other health care provider promptly. You should never disregard medical advice or delay in seeking it because of something you have read here.

The information contained in this document is compiled from a variety of sources (“Information Providers”). Neither Sharsheret, nor any Information Providers, shall be responsible for information provided herein under any theory of liability or indemnity. Sharsheret and Information Providers make no warranty as to the reliability, accuracy, timeliness, usefulness, or completeness of the information.

Sharsheret and Information Providers cannot and do not warrant against human and machine errors, omissions, delays, interruptions or losses, including loss of data.