Caregiving and Cancer: Ideas and Inspiration for Loved Ones of those Facing Cancer

National Webinar Transcript

November 10, 2021

Presented by:

SHARSHERET®
The Jewish Breast & Ovarian Cancer Community

About Sharsheret

Sharsheret, Hebrew for “chain”, is an international non-profit organization, that 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 regional offices in the Midwest, Northeast, Southeast, West, and Israel, Sharsheret serves 275,000 women, families, health care professionals, community leaders, and students. 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, approximately 25% of those we serve are not Jewish. All Sharsheret programs serve all women and men.

As a premier organization for psychosocial support, 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 self-management 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.

Melissa Rosen:

Good evening. Thank you so much for joining us tonight. I want to really applaud you for joining this important conversation about caregiving. It turns out that November is Caregiver Awareness Month.

My name is Melissa Rosen. I am the director of training and education at Sharsheret. I'll be moderating this evening. But before we begin, I have a few housekeeping items to share.

First, I want to thank our event sponsors, without whom these programs would not be possible. You saw their names on the slide. The Florence and Lawrence Spungen Family Foundation, Eisai, GSK, Merck, CGEN and the Siegmund and Edith Blumenthal Memorial Fund. Thank you so much.

This webinar is being recorded and will be posted on Sharsheret's website, alongside a transcript. As always, participants' faces and names will not be in the recording. In fact, because for some, the nature of this conversation might be private, please remember that you can choose to hide your video and even rename yourself on your Zoom square, if you wish. All participants were muted upon entry. Please keep yourself muted throughout the call.

I do want to say that we received many important and insightful comments and questions ahead of tonight's program. Toward the end of the program, there will be an opportunity to ask questions of today's presenters or Sharsheret's staff. You can also add your thoughts or questions in the chat box as the program happens. In fact, I encourage you to do so.

As a reminder, Sharsheret has been providing telehealth services to the breast and ovarian cancer communities for the past 20 years. I recently heard someone describe the past two years as a time of creative connection, and I really do believe that's true. So, we continue to provide the necessary support we always have. We found meaning in the creative ways we've connected with all of you in the past year, caregivers included. And in fact, caregiving, the act of caregiving requires a community. And we'll certainly discuss that tonight.

A reminder, that in addition to our many formal programs, to help women and their families navigate the different aspects of the cancer experience, our clinical social workers are available for one-on-one support. They can answer questions, connect you to appropriate resources, help you process emotions that often arise during cancer experiences and so much more.

I hope all of you already know that Sharsheret has a program for specifically, for caregivers, called the Spungen Foundation Family Focused Program. This program can assist you with the many aspects of caregiving. And each component is meant to provide you with the support you need to best support your friend or loved one.

There is a robust section on the Sharsheret website that includes information about topics such as self-care, long distance support, communication, and so much more. And the page includes the ability to order the free resource kit for caregivers. There's a link in the chat box now to that page on our website. And by the way, all the links we put in the chat box will also be in the follow-up email we send you in the next couple of days. Family focused like all of our support programs and services are 100% free.

As we move into the webinar itself, I want to remind you that Sharsheret is a national, non-profit cancer support and education organization, and does not provide any medical advice or perform medical procedures. The information provided by Sharsheret is not a substitute for medical advice or treatment for a specific medical condition. And you should not use this information to do so, as always seek the advice of a qualified medical professional.

Okay. Let's get to it because I am so excited by the format of today's program. It's a bit different than what we usually do. In lieu of one expert tonight, we have three. Three special people who have all served as caregivers for someone who has faced breast cancer. Three special people whose caregiving experiences look very different from one another. Because just as each person's cancer experience is unique to them, each person's caregiving experience is unique, with different relationships, challenges, practical concerns, and more. And that is what we're going to be addressing this evening. We'll also share some tips to ease the challenges caregiving can present. And have you show your tips in the chat box as well.

Let's start by framing the conversation. As we educate communities across the country, or provide individual support through our clinical team, we at Sharsheret spend a decent amount of time redefining the word caregiver. People assume that there is a caregiver, whether it's a spouse or partner, a parent and adult child. Everyone else is simply just helping out.

Right now, before we hear from our speakers, I want to clarify something. Anyone who assists someone facing cancer in any way is a caregiver. With their partner, parent child, friend, neighbor, or something else, they are worthy of that important title of caregiver and the support available to caregivers.

Cancer impacts so many aspects of a person's life, including physical and emotional. And there's a trickle down. With cancer also impacting children, other family, friends, and more. With so much impacted, it often takes more than one caregiver to address a patient's needs or concerns. And by the way, not everyone is capable of meeting all of those needs. Perhaps someone is more than happy to accompany a friend to screenings or blood work, or even provide homework help for children, but gets overwhelmed at conversations about cancer. Maybe someone is excellent at helping organize medicines and appointments, but would be lost if you asked them to cook a healthy meal for your family. And that's why people facing cancer benefit from a team of caregivers. Each of these people are caregivers, much needed, much appreciated and much loved caregivers.

No matter how much or how simple, it is important for you to understand the positive impact you are having, or you had on your loved ones during their cancer experience. That's so important to keep in mind.

Okay. Our first speaker is Michael, whose wife was diagnosed with breast cancer many years ago, but recently had a follow-up surgery. So, we're going to spotlight Michael. Make sure he can unmute himself and ask him to join us. Thank you.

Michael:

Hi, everyone. Wow, I'm really spotlighted here. Okay. So, our story started about a little bit more than 20 years ago, and it was a couple of weeks before my wife's birthday. She's 56 now. So, she was 36 years old at the time, or just about 36. And it started when she came to my office crying. I was working at Fox Studios at the time. She came to my office, and she was crying. And they said they found a lump in her breast. Sorry.

So, I'm a very organized and pragmatic kind of person. So, we went through all the steps necessary to figure out what our course of action was going to be. And as part of that, my wife is adopted. She has four older brothers. And she was adopted. And so the genetic testing was a bit complicated.

Her mom had kept a lot of the information hidden away in the safe, in the basement, somewhere in their house, kind of thing. And I remember her mom coming to the genetic counselor with us and opening up her purse, and sticking her hand in to the bottom to get out a piece of paper. And that was the first time we heard any information related to my wife's biological parents.

So, we decided the course of action. And by the first week of November, so from the middle of October to the first week of November, we had everything lined up. My wife decided because of the genetic testing came back positive for the BRCA gene, she decided to have a double mastectomy at the time. And she had a goal originally to by Thanksgiving time. So, three weeks later to be able to get on a plane... Sorry. Get on a plane and go to Michigan. We're in Los Angeles. Get on a plane, go to Michigan for her nephew's Bar Mitzvah, her brother's son. I'm happy to say we were able to do that, drains and all on the plane and with our two kids at the time, who at the time were five and eight, Talia and Jeremy. And they're now 25 and almost 28 on Friday. He'll be 28, Friday, Saturday, one of those two days.

So, we went to Michigan. We came back. And then my wife started her chemo. And the chemo lasted through June. I think it was once every three to four weeks. And her parents came to every chemo that she had, so did I. And they were there to help us after chemo. The week after chemo was a very tough time. So, they were there to help us after chemo.

And my wife's next goal was to, at the end of June, go and work at Camp Ramah in Ojai, California, where she, and all her brothers and all those kids, and she was there as a [inaudible 00:11:54], which is like a counselor for the counselors, if you will, kind of thing.

So, she was able to go that summer, bandana with no hair. Bandana on her head. And so, now we're coming to around August, and she had her surgery to get her implants or breast implants. And I think it was a small procedure at the time. It was the prep work. It was a small procedure at the time. And so, her brothers flew in from Israel, from Michigan, from Colorado, and then one drove from Tarzana, which is close by here in California for the surgery. It was on a Friday. It was an outpatient surgery. And she had the surgery. And we had Chavez dinner together Friday night, all of her brothers at her parents' house. And then everyone, mostly everyone had left Monday morning. Her dad went to the gym and had a heart attack and he passed away.

So, the caregiving dramatically switched, if you can imagine what that might've been. So, we went through that. And I remember that during that time there were a few things that I learned that I still think about today. One is a story that I share with people about our kids who were five and eight at the time. And when my wife came back from her first surgery, from the mastectomy, there was no way I could handle the craziness in the house from a five and eight year old that existed prior to my wife's diagnosis, right? All I had to do was get up and do what I could to get out of the house and get to work. Right? And the craziness was left behind for a second. My wife was a school teacher at the time and she brought the kids with her to school.

So, my mission number one was for the kids at five and eight to get out of bed by themselves and get them get dressed, and have them come to the kitchen and not figure out what they wanted to do from all the different choices that were there. So, I actually laminated three cards for them each, frozen waffles, frozen pancakes, or cereal. And they had different Tupperware containers. And each by the time I got to the kitchen, they knew that they had to have their little card in the Tupperware container, so I could get breakfast ready, so we can get them out the door to get the school on time.

So, for me, organization was a big thing. Boundaries, understanding boundaries was a huge thing for my relationship with my wife. When she wanted to be alone, I had to respect that even though I wanted to know maybe how much she was feeling or what she needed. And she just wanted to be left alone.

And also boundaries with the community that came to support us. Right? They wanted to help a lot, but we didn't really feel, after a while having people bring you meals and coming into the house became a whole event in itself. Right? So, we had decided that maybe they would leave the meals out front or just drop it off. And we shared with them that, "Please, just drop off the meal and just go." Right? So, we learned a few things like that.

And to wrap this up, there's for those 20 years a couple of things we're dealing with. My wife just had a surgery. Again, all good, not a reoccurance, but rather. I don't know how to say it, but the implants needed... The warranty expired on her implants. How about that, kind of thing, right? Because it's been so long. And she's been so healthy for 20 years. And now we're having discussions with our kids, our daughter, 25, and our son who is going to be 28 because they need to do some testing themselves now. So, that's the story.

Melissa Rosen:

Wow. Wow. Thank you so much for sharing such a personal story. I think it's so helpful when we hear what others have gone through and how they coped, and even what they learned because it supports us as we try to do better for our loved ones and for ourselves. And I love that you talk about boundaries. That's an important thing. And I will take away laminated cards, breakfast cards from this. I think that's something we can all use, whether we're caregiving or not. But thank you very much. We really appreciate it. And we're so happy to hear that your wife is doing well.

Michael:

You're welcome. And she's in the audience right now.

Melissa Rosen:

Amazing. Okay. Next we have Rachel [Taisha 00:17:39], who is actually a member of Sharsheret, Extraordinary Clinical Team. She will be sharing some thoughts about how a cancer diagnosis can impact a marriage or a partnership. And like I said, I want to take a second to acknowledge that cancer can and sometimes does do just that. And we talk about a lot of things, but somehow this is a hard one. So, I'm grateful that Rachel will share some insights tonight. So, let's spotlight Rachel and bring her to... There she is. Okay.

Rachel Teicher:

Hi, everybody. Thank you, Melissa. So, as she said, I'm Rachel Teicher. I am one of the members of the clinical team at Sharsheret. And my main focus is to be here to support both the women or men going through a diagnosis or their family members, or caregivers, or friends of any type.

And so, I just wanted to start off the night by saying, first of all, thank you, Michael, for sharing all of that. I think, when you can hear it from someone who's gone through it directly, it makes such an impact. And I think I want a blanket statement of, everyone can walk away from here, whether you are currently a caregiver, going through it at the moment, or you've gone through it in the past, just knowing that I hate using the word normal, but it is normal to have both good changes and bad changes in your relationship, no matter who you are, whether you're a spouse, a friend, a family member, anybody, anybody who's involved in someone's life, who's going through cancer. And I think just remember that it's okay and normal.

And just keep it in the back of your mind always that ups and downs are okay and normal. And that's the natural course of things. And please not to feel alone in it. And that you are most certainly not the only one dealing with that, if that's what you're seeing. You're seeing changes, and scare and worry in your relationship. Because again, cancer diagnosis is a big deal, and so things are going to change naturally.

So, there's this one story that someone shared with me. And this is something that I hear often from spouses actually, how they're concerned about, are they doing the right thing or are they saying the right thing? And they think that their spouses are mad at them all the time and they don't know what's happening.

And there's one particular instance, a woman shared with me. It was coming time for her to make some choices about her surgery. And she felt that her husband should really be a big part of that. She wanted him to help make that decision. "Should I remove just the breast that has the issue? Should I take both off? And as precaution, what should I do? And how will this change me going forward?" And she kind of presented him with that and said, "Okay. So, what do you think I should do?" And his answer was very simply, "I think you should do whatever you want, whatever you need." And that was kind of it.

And she held onto that for a little and realized she was so unhappy with that answer. That is not what she wanted to hear, and it was certainly not enough. And it ended in like this explosion of frustration like, "How could you just say that to me? I want your help. I want your input." When he was so taken back that she was upset because what he meant deep from the bottom of his heart out of love and care was, "I just want you to know I'll be happy. I don't want you to feel pressured to do anything because of me. Do anything. I want you to be healthy, so do whatever you have to do, and I'm good with it." And that's not what she heard or understood. And so, of course, the key there is communication.

And I think this is something that I love to share with everybody, I speak to, again, spouses in particular, because you're usually there with your partner the most often and involved in the toughest choices. But for anybody, any person involved in a relationship with somebody going through cancer, a friend, family, anybody, communication is key. And actually not just thinking they understand what you're saying, but really diving a little deeper and saying, if he would've said that to her from the start, right? She would've been totally fine and said, "Oh, okay, thank you. I appreciate that." But it's getting your point across. And especially for the person who's going through the diagnosis themselves, they already have so much running through their mind, fear, anxiety, concern. And it's a lot to deal with physically and emotionally.

So, doing your best to go the extra mile can be super helpful. Even if you think normally they'd understand you, just go that little bit extra and maybe communicate a little more or add a little more in to make sure you're really showing them that you're getting your point across and what you truly mean.

And on the other flip side, there's also a story of a woman who shared that, actually, she comes from a very traditional marriage. Her husband worked and she stayed at home and took care of the house, and the children. And that's what things always were for them. And it wasn't bad. It just was. And then she was diagnosed. And she could not do anything she did before. And similarly, to like what Michael said, he had to figure out what he was going to do with his children. And this was the same thing like, "Okay. I got to figure out a game plan now."

And so, the husband, he actually reached out to us and all he wanted to do is figure out like, "I want to be more for my wife. I want to do everything I can." So concerned. And he had to take on this role. And in the end, it brought their marriage even closer. And instead, there wasn't any kind of strife, but more positivity, and realized how much they needed and respected one another. And they didn't quite realize that before this. So, there's both sides of the coin, and both can happen, and anything in between. And there could be some days that are beautiful like that and some days that are really hard. And I think it's just important to know you're not alone.

And that's one of the reasons we really wanted to bring this up tonight, is because I think a lot of people sit back feeling guilty, if they're feeling frustrated at their partner, who's going through cancer, and you shouldn't because it's hard. It's hard on you as a caregiver. We know that. Of course, it's hard on the person going through the diagnosis, no doubt. But for you, it's also a big burden emotionally and physically to take on and just know you are a hundred percent not alone in it. There are others who feel like you, and also we are here to support you.

So, we're here to give you that advice. We're here to be your sounding board, because it's really important to have that. And also, aside from the communication and really asking your partner what they need, I think also it's okay, some people do turn to therapy. That shouldn't feel like something taboo or bad either. It's okay to have all these things. It's a big life change. And I think as long as you're communicating with your partner and asking of them to share that this is all coming from a place of love and care, and showing that that's all you really want in the end, that even the tough times can be worked through.

Melissa Rosen:

Thank you so much. [inaudible 00:25:15]. Sorry, I accidentally got muted. Thank you so much, Rachel. Yeah, I think one of the takeaways there is of all times this is not a time to make assumptions, and use those communication skills. Thank you.

Okay. Our next presenter is Shauna. Shauna has the unique experience that her mother was diagnosed after her own breast cancer experience. So, we're going to highlight Shauna right now. She's going to share a little bit of her story. Welcome. Thank you.

Shauna:

Hi, good evening. And thank you so much to the fantastic Sharsheret's staff for putting this together. I have enjoyed, learned and benefited so much from their virtual programming and events.

Being far away from the people you love is never easy. Being far away when they are going through something hard is incredibly painful. When I was diagnosed with cancer at 25, my parents were overseas, and they found out over the phone. Over 10 years later, I sat on my couch in Ohio while my father calmly told me and my husband that my mother has a little cancer.

I am a social worker. I'm an event planner. My whole world is based on relationships and showing up. And here I was in a different state when one of the most important people in my world was dealing with something. And I was the only immediate family member with the firsthand knowledge of the experience. The feelings, shock, fear, anger, sadness, anger, guilt, anger. There was so much that was triggered with the news. I was processing the information as a daughter, as a type A details person, and as a breast cancer survivor.

People often ask me what they can do for a friend or relative who's going through an illness. "I was thinking of a basket with candles and maybe a snugly blanket." They would ask me. Then I would ask, "Who's doing their laundry and making sure they have food in their fridge?" I'm really good at anticipating needs. And here I was in the wrong place during this difficult time.

As the weeks wore on, I was able to be supportive from afar, knowing that there were closer family members that were involved in the more practical details. When I was able to be there, I quickly learned that I'm not a good waiting room person. What is this crazy place where you're just supposed to sit there and stare at the door for hours on end? As crazy as it sounds, it's so much easier being the one under anesthesia.

Seeing my mother in the recovery room was probably one of the most difficult moments of my entire life, but I am so grateful that I was there, knowing that I could help her in a way that no one else could. I could never say that I repaid her for taking care of me during my cancer journey. She has really never stopped. But I recognize that the caregiving that I did really did have an impact. And that was incredibly empowering for me as a daughter and as a survivor. I think that we can define caregiver in so many ways. For me, it was part daughter, part survivor, part friend, but never underestimate what you are doing for your loved one. Thank you.

Melissa Rosen:

Thank you so much. What a unique experience and not an easy one. We appreciate you sharing your story. And I know that your mother appreciates all that you've done for her.

Okay. I want to welcome Rachel back to the screen for just a brief moment. As we've discussed, some people caregive without even realizing they're taking on the role of caregiver. Many times it is friends that fall into that category. So, I think it's so important to note that someone can be an essential caregiver without being the primary caregiver. So, Rachel is going to talk for just a moment about caregiving as a friend.

Rachel Taisha:

Hello, again. I actually have a quote up next to me. So, if you see my eyes go over, it's because I'm paraphrasing. It's so amazing, what a woman shared with us that I thought was so great to share with all of you. And really piggybacking off everything you guys have all already said, as caregivers, it's really like that. It's the theme of making sure that all the pieces of the puzzle are covered for these people and communicating, and just the boundaries, and figuring out what they need, and trying to be that person for them in so many ways.

And this person who was a friend of somebody going through cancer said that, when she thinks about what being a caregiver mean, she didn't quite think of herself that way, because it's like, "Well, am I a caregiver? I'm her friend." But what she thought of was, you always tell your friend, "I have your back, right? I always have your back. I'm always here for you." And it's in these moments where, yeah, you're like, this is what that means, right? And unfortunately, you don't ever want there to be a moment like this, but sometimes there are. And this is where you have to put that line that you always say to your friends into action.

And she said it was so gut-wrenching to watch her friend go through this and not be able to take away pain or give her a magic pill to do something to make it better. But she knew she could do something. And while it wasn't a magic wand, it was more of, "What can I do to help you?" And she felt it was a privilege for her.

And when I read this, it actually made me laugh because I often say to women, when I first speak with them, they say, "I'm so nervous to ask for help. It makes me feel bad." And I sit with the women who say that to me, my line always to them is, "Actually, think of it like you're doing someone a favor." And they laugh. And they're like, "What do you mean?" And I say, "It's because people want to help. The people who love and care about you want to do something for you, especially right now. They wish there's something they could do to help. So, it's actually what your job is, instead of feeling guilty, you're going to tell them exactly what they can do. And then you're really doing them a favor, because all they want to do is help. So look at that, think of it that way. You're just helping them to help you."

And I always say to them, "Hey, listen, now is your opportunity, instead of letting them," like you said, Shauna, just send you a nice basket with a pillow or slippers, or blanket, which is nice, by the way, saying, "Hey, do you need a meal tonight? Or do your kids need picking up? Can I help you with laundry? Anything." That's the practical things that I always suggest. Ask your friends to do the things you really need. And don't be shy because you're doing them a favor.

So, I'm happy to see that this friend wrote in that they feel that. It was a favor to them to be able to help. And so, I'm glad that we're all on the same page. And I think it's important to take that away and realize whether you're the person going through it, or you're the person giving the support that, again, here's that pattern, communication and being there. And it's the best thing you can do. And it's helpful in more ways than you know.

Melissa Rosen:

Thank you so much. Okay. Our final speaker is [Adera 00:32:52]. Adera was a source of care and support for her sister during her breast cancer experience. Can we highlight Adera? Perfect. Welcome.

Adera:

Hi. Thank you. Oddly, I'm feeling a little bit nervous now to speak. And that's not typical for me. I do a lot of public speaking in my work. And I think it's because I want to share with you my experience with my sister and caring for her or supporting her, or witnessing her journey. And I feel like I'm going to say some things that are really vulnerable. So, I'll go for it. And I just want to add before I start that my sister, Shoshana knows everything that I'm going to say and she's totally cool with it. So, if anybody feels like I'm violating her privacy, I have her authorization to discuss.

So, I want to talk a little bit about some of the really hard parts for me about watching her go through her cancer journey, including... And journey also is always a hard word for me because I don't know, journeys seem to have evocative of something pleasant, and it wasn't pleasant. There were times of humor and there were times of happiness in the middle of all of it, but it certainly wasn't pleasant. And she went through treatment for about two years, including multiple surgeries.

And I think that I thought hearing the diagnosis was going to be the hardest part, but that was like where I went into more creative mode like, "Oh, I can order really cool things from Amazon and put them all in a chemo bag that she can bring with her. And what's her favorite show? And what can I do to make her first chemo day really..." I was about to say the word fun, but I'm more meant distract her with things that made her happy. That's my zone, right? Being creative, I love that. So, that was like, "Okay, here is where I can take my feelings, put them aside and focus on this piece of creativity." And it got harder and harder as it went.

And I think it got harder and harder for me as I watched her become more and more weak from the chemotherapy and struggle to be a mother, and struggle to be a daughter and sister, and a wife, and to work as much as she could nearly full time throughout the process. And sometimes I looked at her choices and I was so upset by them. And that's part of what I want to share with you, because I want to share that that's a natural thing to say, "Everybody is asking if they can do something for you. Why aren't you saying yes? I can't understand why you're not saying yes. I can't understand why you're not letting us make your life easier."

And there were times that I think she needed to get there on her own, sort of what Rachel was sharing before. But as a loved one, especially my sister's journey happened during COVID. So, there was the ability to be present. There was nobody that could move into her home and care for her children with her. There were a lot of things we couldn't do. And when we could offer the things we could do, and there was sometimes resistance, that was really, really frustrating. And it is obviously at the root of that, there's love. If there wasn't love, there couldn't be that level of like frustration, but it existed for me. And I think along the lines of what Shauna was sharing, a feeling in a space of helplessness.

And I would anticipate for many of you, if you're going through the caregiving process, that there will be days of complete helplessness, where you look at the person you love and you see them in a space of pain or physical pain, emotional pain, and actually, there's nothing you can say and nothing you can do to make it better because it's their journey. And you're there to be beside them. But you can't take that pain for them. And that can sometimes, I think it can be incredibly disconcerting and upsetting.

And also, one of the things I want to share is that it is okay to feel a sense of resentment. I got to that place a little bit with my sister when my job, so she was at the hospital across the park from where I live. And when she was there on weekends, and inevitably she was always there over the weekend, I would walk over on Saturday morning and spend the day in the hospital with her.

And I had this incredible fear as I would walk through the park thinking, which Shoshana was I going to find? Was I going to find the Shoshana that had an okay day and was sitting back in her bed in pain and in discomfort? Or was I going to walk into her room and find her crying hysterically and in so much pain that she couldn't even articulate the level of pain that she was experiencing, because she was so consumed by the feelings of pain?

And as I would cross the park, I wouldn't want that one for myself. I wouldn't want it for her, but I also wouldn't want it for me because I knew that if I had walked into the room and I saw her like at, that I would have to be strong and figure out how to say the things that were just enough to support her to not overly... I'm grasping for word because indulge sounds terrible. But to say, "I get that you're in pain. We need to get a up and walk around the nursing station. You need to move your legs. You need to move your body. This is not good for you to stay still."

And to be somebody who in that exact moment was trying to be empathic, was trying to be loving, was trying to be supporting, and also was trying to say, "I know this is going to cause you pain, but I can see beyond your pain for what might be more helpful for you."

And how do you communicate all that with somebody who is going through what they're going through and not hurt their feelings or not make them upset? And so, creating this, there was a time I never felt like I was... My sister and I have an incredible relationship. I never felt that there was a time where I was walking on eggshells, but I certainly felt that desperation of, what is the thing to say right now and how do I get there? And that was incredibly challenging for me.

And just as a side point, I do this. I am a medical [inaudible 00:39:36] in a hospital, working with many patients, many of whom are facing chronic, critical and life threatening diseases. And it comes much more naturally, and for me in that space. And bringing it into my sister space and trying to figure out how to be the loving sister and the supportive sister, and also the sister that pushes and challenges.

And I asked Shoshana permission if I could share this story really quickly. But she was having a gag response every time they flushed her IV. And I kept saying to her, "I think a really good thing to do would be aromatherapy. So, sniff something while they're doing it." And she wouldn't have it. She just was like, "It's not going to help." Or she just didn't want to entertain the idea. And I brought like a spray bottle of lavender with me to the hospital and I was like, "Do this." And she really didn't want to do it. And then one time I was just stuck it under her nose while they flushed her veins. And she's like, "Oh, that works." And I just was like, "I can't handle it."

But at the same time, it's kind of that, I would say be persistent, be loving, be present, and also allow people, the people that you're caring for, or allow for the fact that the people who you are caring for might not be able to receive it in the moments that you want to give it, but something eventually will land. And so, if your timing might not be always synchronous, but I do think that as long as you show up with love and authenticity, then there is a time where they'll be able to hear what you're trying to say, even if it's not in that moment.

And I guess, I have one last thing to say before I... I mean, I could just keep talking, but I have one last thing to say. And that's self-care is a term that gets used a lot. And I feel like a lot of times it's synonymous with like, do yoga, do meditation, treat yourself to a spa day. And those things can be self-care, but self care also can be, "Today, I can't be your caretaker because today I'm not in the mind." I mean, if you have the luxury. I understand there are times when people don't have the luxury. But if you have the luxury of saying, "Today, I'm the person who needs support. And I'm going to find somebody else to be with you." Or, "I need to separate rate myself from you in order to come back and to be able to be present for you in the way that I want to." That's also self care.

And as a caregiver, we sometimes feel like, and it is their journey, but it's also, you are having a journey that's right next to them. And to be aware that you are allowed to experience pain and discomfort, and anger, and resentment, and all of those feelings, and you are entitled to experience those feelings.

And as I wrote this recently, but witnessing suffering is suffering itself. And you need to care for yourself through those moments. And I think I'll just stop there.

Melissa Rosen:

Thank you so much. What great insights. I want to thank all of you for sharing your stories. I want to give people an opportunity to ask questions. And so, while I talk about one more thing, super briefly, if you have any question, like I said, for any of our speakers tonight, for Sharsheret, or if you have things that you've done that you want to share, please use the chat box. And we did get some questions in ahead of time, but please ask questions now, too.

If we could unspotlight everyone at this point, I want to just say as a caregiver or someone offering support, no matter your relationship to the person facing cancer, please, as Adera said, be aware of your own needs. Her cancer experience will have an impact on you because cancer invokes strong emotions in all of us. It is important to have a support system of your own, whether that's a friend, a colleague, a rabbi, or clergy member, or a mental health professional, including someone from the Sharsheret clinical team. As a caregiver, you can call Sharsheret and speak with a staff member or receive resources through our family focus program. And by taking care of yourself, you will be better able to support the person that you love. And that's so important.

Okay. Yes, exactly. So, somebody just said, "Show up, give support and help caregivers as well." a hundred percent. So, we do have some questions that I'm going to ask. Can we unpin people? Is that not happening or is it happening? Maybe it is unpinned. Okay, great. I see it's unpinned.

Okay. So, please put your questions in now. But I'm going to ask some of the questions that came in ahead of time. Okay. So, as long as we're talking about self care, let me start with this first one. "I know that self care is important, but that doesn't mean I have time for it. Between caring for my spouse, our children, the household, and my job, what can I do?" So, that speaks exactly to what Adera was just saying. And it is important. And it alludes to the story that Rachel spoke about also. Yes, when we become caregivers, we're taking on so many extra layers of things. But it is important to find moments of self care. Not on my list, but an idea that I will now add to my list when I talk about this is saying, today is a day I need to find someone else to be with you, just because I need to regroup or take care of something else.

I want to share that that there is a lot of information about self care on that page, on our website that was in the chat box, but also will be sent in the follow up email. But a couple of things to point out that don't take a lot of time necessarily, because that was the crux of this question. You need to find your own support system, a friend, just what I said, a friend, but it doesn't have to be a formal call to Sharsheret, although, definitely do that too, but it could be having a running conversation with a friend that's lighthearted on text throughout the day, just to get you to smile a few times. Or it could be meeting, if you have to do a supermarket run, and it's not COVID, or it's a little safer where you are now, having a friend meet you and do the supermarket run together. You're accomplishing something you need to accomplish, but you're also getting the support you need and the company you need.

Take a few minutes before bed, when everybody in the household is in bed to regroup, to read a book that you enjoy, to make notes about what need to be done tomorrow, so you can offload it from your brain and get a good night sleep. There are a lot more suggestions on our website, but those are just a few of the things that don't take a lot of time.

Okay. So, I'm going to throw this question to to Rachel. Another question came in ahead of time. "How can I support my person when I actually don't believe they're trying to maintain a healthy attitude? And I hate to admit it, but sometimes it even feels like she's using cancer as an excuse."

Rachel Teicher:

Yeah. So, that's a tough one. I think actually some of the things Adera said hit a on this question, specifically, because when you're sitting back and watching somebody you love go through something so difficult, but at the same time you feel like there's moments where there could be positivity thrown in there, or it doesn't have to feel so dense and tough all the time. And maybe that would make things easy, because you know it would make things easier for you. And you think, "Okay, it would make things easier for them too." I'd like to call it the sandwich method. I was taught this by another mentor of mine.

And I was thinking about this the whole time of year when you were speaking as well, when you had said, what's like a nice way to tell the person you love that you're frustrated with what they're doing and help them out? And this to me is a great way. And I share this all the time when people are speaking with me. If you say something really nice and positive, before and after, you're saying the difficult thing that you have to get across to them, or the thing that's maybe not as great, it comes off as differently. And they hear that first and last. And that's what resonates with them.

So, if you feel that someone's being super negative all the time and not willing to even in the few moments that you can do something happier, positive, or you have a suggestion like Adera's for example, where you really think it could help, and they're just totally refusing to take your advice or anything like that. You can say something like, "Listen, I love you so much, or I care about you so much." Whatever language you use. "And I can't imagine what you're feeling going through this. And I'm sure it's so hard on you. And I would never want to take that away from you all. I want to do is be there for you. But I noticed that we're never having any moments of positivity, any moments of happiness. And while I'm sure it's so hard for you to feel those moments of happiness or positivity, I want what's best for you. And I feel like maybe even taking a few moments here and there could make a difference.

So, I'm coming to you because I want to do anything I can to help with that, even if it's five minutes or 20 minutes that we watch a show that makes you laugh. Do something that distracts you. Anything we can to have a few moments of positivity. Or whatever it is, like I said, that you're trying to share with that person. If it is that you're trying to have them get help. "I hate seeing you struggle. I care about you so much. And I'm sure it's so hard to ask for help. But hey, why don't you pick one person that you're comfortable with to ask for these things and they can be your designated person to share with others. And I'm only saying this to you, not to stress you out, I'm doing this because I love or care about you." And like I said, sandwiching the good and bad, I often find that really helps. And the feedback I get is that people have an easy time communicating that way too.

Melissa Rosen:

That's a great thing to try. Absolutely. So, I see a couple of posts have come in on the chat box. And I continue to encourage you to share something that's been helpful to you or a question you may have. But somebody did share that they are a survivor themselves and would definitely have been receptive to hearing from their husband that he needed a little alone time or away time. So, if you're worried that it will be upsetting to the person you're caring for, we have a survivor who has said she would've definitely been receptive to that.

Another person shared that as a caregiver for her husband, who has passed from metastatic breast cancer, she always listened and helped him discuss his options. I think this is referencing back to that story, Rachel, you shared at the beginning. But it always felt it was his decision to make, that even if she disagreed, she had to honor his decisions. And that's important. Have the discussion, be part of it, but honor their decisions in the end. I think that's a great attitude and important thing.

A couple of more questions here, so that we got ahead of time. So, actually I'm going to leave this open to any one of our three callers, or not callers, excuse me, speakers tonight who want to respond to this.

So, someone asked, their daughter is having reconstructive surgery soon and she wants some tips at that particular point of the cancer experience to encourage her daughter or to help her daughter. So, if anybody, Michael, Adera, Shauna has any thoughts on that in particular?

Adera:

I mean, my sister's surgery was an all in one, and then followed by... She's spoken about her journey a little bit. Followed by multiple corrective surgeries. So, it was a challenging course for her. That's not a typical course.

So, I think it's hard for me to know if that question is about like, how do I encourage her to feel positive? I'm not sure exactly what what's being asked. But I really do think the little things make a difference. I know I laughed at it before about making the chemo bag or those kinds of things. But when I made the chemo bag, I also pulled a bunch of people who had gone through chemotherapy and asked them, it wasn't what I thought would be appropriate. And they said it gets cold and have a blanket, or you get chapped and have like skin cream, but odorless. Make sure it's odorless because odors can make... All of those pieces, but I try to infuse it with some humor too. So, a blanket that had a character from my sister's favorite TV show or something like that.

So, I do think those little things, as long as they're also encouraging, that can be there for her hospital stay. I think for me that might be one way.

And the other is children. Children don't want to hurt their parents. And parents don't want to hurt their children. And so, I think giving her space, if she's not the type to say, "It's okay for you to tell me you're in pain. It's okay for you to share how you're feeling. And I'll share how I'm feeling." And making that like an open area. Because I know I had that with my sister too. I was able to tell her how I was experiencing her illness. And I was able to hear from her, sometimes too much. No, I'm kidding. About how her experience was going. So, that would be my two thoughts.

Melissa Rosen:

Those are very helpful. No pressure, but Shauna and Michael, do you have anything you want to add?

Shauna:

I just, I think there's something interesting about different parts of the journey. There's something really cool about the beginning where everyone comes forward, and they think it's a couple months or even a year, or whatever of that crazy part of the journey, and then slowly but surely a lot of people drop off. They don't really understand what it's like.

One of the things that I talk about a lot as a survivor and as someone who's been working with a lot of people who've gone through it is that sometimes after those, that first year or two of initial treatment, there's a lot more, a lot more for a long time that that goes on. And it's not the cool part of being there for somebody, because first of all, at certain points, you just, maybe it's more private. Maybe it's just not something you want to be sharing. Those are times when you really, really need be some extra help, but it's not that initial shock of diagnosis where everyone comes running. It's that piece, it's like, when you're a mom and after a couple weeks, everyone leaves and you're like, "Okay, what do I do now? I still need help."

So, I think that piece of treating some of these additional stages of the, I also don't like the word journey, but of the process of all of these pieces that have to do with the cancer experience, they are either just as hard, maybe harder. Some of them there is a much bigger emotional toll. The initial cancer experience is so overwhelming that you don't even understand which way is up, but then you're a little more of yourself and all of a sudden you're doing something else that's incredibly hard, and it's like, "Wait a second. What just happened?" And you also really need people.

So, I think seeing it as just as hard as chemotherapy, even though maybe physically, it's a different experience, there's a tremendous amount of emotion and physical discomfort and pain, and figuring everything out. You're literally getting used to a new body. So, I think just looking at it like another step of this whole thing and not looking at it as like, "Oh, it's another surgery, but you're so healthy. So, not a big deal." It's really a big deal.

Melissa Rosen:

That is also very good. And I say, you've both done a great job at addressing some of the deeper content there. So, I'm going to add just, if the question was more about, what can I do to make her more physically comfortable to help her prepare? So, there is a list on our website, but a couple of items when someone's having surgery, button front shirts, because lifting the arms is hard. Or a foam wedge to help a person be able to get in and out of bed because they're never in a fully lying down position. Things like that can also be very helpful and important, but not as deep and thoughtful as the two things that Adera and Shauna were talking about.

So, it is just about 9:00. Adera has some more thoughts in the chat box for anybody to see. But just as we're ending, I just wanna thank you all again for joining us and to the wonderful speakers who shared their experience.

I once again, want to thank our generous sponsors, the Florence and Lawrence Spungen Family Foundation, which as you've heard funds our family focused caregivers program, as well Eisai, GSK, Merck, CGEN, and the Siegmund and Edith Blumenthal Memorial Fund.

A reminder that Sharsheret is here for your loved ones and for you to provide that one-on-one support or to help with programs. I encourage you to reach out to our clinical team to see how we might be able to help you. Remind you that everything is completely customized, completely confidential, and completely free.

We've spoken a bit about Family Focus tonight, but I want to take one moment as we finish up to share one more relatively new and important tool at your disposal. Sharsheret recently launched a caregiver's Facebook group, a private caregiver's Facebook group. It's a wonderful place to benefit from other group members experiences, to share your own, to gain support. The link to join that group is in the chat box right now. Again, you have to join the group because it's a private group.

And then finally, please take a moment to fill out a brief evaluation survey that is linked in the chat box now. You can click on the link right now and still hear the rest of the webinars, final thoughts. And it's so important. We really do base future webinars on the response we get from these evaluations.

And the last thing I want to share is that we have several exciting webinars on a wide range of topics planned for over the next few weeks. Next week, we are dedicating a webinar to men's health and hereditary cancer. This program is open to both men and women.

We also have a Sharsheret in the Kitchen scheduled with cookbook author, Paula Scher, who will share some lightened up desserts for the holidays. And the month of December is filled with meaningful programs. So, please check out our website regularly to see what topics are coming up.

Somebody just asked if this is being recorded. Yes, this is being recorded. It should be up on our website by early next week at the latest. And as you've already registered, you will be notified by email as soon as it's available.

And that is it for the evening. Again, thank you so much to all of you. And if you have more questions, if you have any ideas, either share them in the evaluation or email, clinicalstaff@sharsheret.org. And have a wonderful night. Thank you.