

Redefining Life After a Cancer Diagnosis: Why “Survivorship” is such a Tricky Word

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Re-defining Life After a Cancer Diagnosis: Why “Survivorship” is Such a Tricky Word

Melissa Rosen:

I want to thank everyone for joining Sharsheret today for an important conversation about the word survivor and the idea of survivorship. Yesterday, was actually National Cancer Survivor's Day, and today's program was designed to recognize that, because by just being here today, we all have something to celebrate. No matter where we are in our cancer experience, no matter what we call ourselves, we can all celebrate the fact that we are here today, myself included.

Melissa Rosen:

My name is Melissa Rosen, and I am the Director of Training and Education at Sharsheret. I am also a two time cancer survivor. Before we begin, I have a few housekeeping items to share. I want to thank our program partners on this important webinar. All fantastic organizations that we work with to accomplish our shared mission. Cancer Support Communities is a network of 175 locations including Cancer Support Communities, and Gilda's Clubs that provide support to those impacted by cancer.

Melissa Rosen:

Also, partnering with us today are Barbells For Boobs, which works to redefine the standard of care in breast health, and improve quality of life post-diagnosis, and Life Well Lived, which shares science, nutrition, life style, and more to improve the lives of survivors. And of course, our event sponsors, without whom these programs would not be possible. Thank you to Merck, Novartis, and CGEN. This webinar is being recorded, like all of our webinars, and will be posted on Sharsheret's website along with the transcript. But, participants faces and names will not be a part of that recording.

Melissa Rosen:

In fact, though, for some, because of the nature of this conversation, it might feel private, please remember that you can opt to choose to hide your image, your video, or even rename yourself on your Zoom square, should you wish. All participants were muted upon entry, please keep yourself on mute throughout the call. I do want to say that we received many important and insightful comments and questions ahead of today's program. Toward the end of the program, there will also be an opportunity to ask additional questions, and any of today's presenters questions.

Melissa Rosen:

You can also share your thoughts and questions in the chat box as the program happens. As a reminder, Sharsheret has been providing telehealth services to the breast and ovarian cancer community for 20 years. And I heard somebody recently describe this as a time of creative connection, and I really do believe that's true. As we continue to provide the necessary support we always have, we found meaning in the creative ways we have connected with you all during the past year, almost year and a half. We truly are a community.

Melissa Rosen:

A reminder, that in addition to the many formal programs to help women and their families navigate the different cancer aspects, our clinical social workers are available for one-on-one support to answer questions, connect you to appropriate resources, help you process the emotions that often arise during the cancer experience, and so much more. And this is as good a time as any to remind you that Sharsheret's support does not end when active treatment ends. We provide support, resources, and guidance throughout survivorship, both immediate and longterm.

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Melissa Rosen:

And I want to remind you that our Thriving Again Survivorship Kit is a wonderful resource, and if you haven't ordered one, it would be a great opportunity to do so. It's all about living healthfully, beyond cancer, both physically and emotionally. Comes with a gorgeous cookbook. It comes with exercise bands, and so much more, and it's completely customized. In today's evaluation, you'll have the opportunity to request an order form. The kit, like all of our services, is 100% free.

Melissa Rosen:

Okay, as we move into the webinar itself, I want to remind you that Sharsheret is a national, non-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. As always, seek the advice of your physician or qualified health care provider with any questions you may have.

Melissa Rosen:

All right, let's get to it. I'm really excited about the format of today's program, because it's a bit different than our past programs. So, there are so many when we talk about survivorship, so many things we could be talking about. We could talk about the transition from active treatment to survivorship. We could talk about the different types of healing that accompanies survivorship. We could offer a medical presentation about healthcare after a cancer diagnosis.

Melissa Rosen:

Today's webinar is a conversation about the idea of survivorship. And even the word survivor, because neither of those, as you'll see today, are as simple as they appear. Today we have some wonderful Sharsheret callers, each with different cancer experiences, sharing their thoughts about the experiences, and how that experience informed ideas regarding survivorship. We also have an amazing holistic therapist joining us, to help us each [conquertize 00:06:12] our own ideas about survivorship.

Melissa Rosen:

Which reminds me, please be sure to have a piece of paper and something to write with handy. But before we get to those presenters, let me, if you will, frame the conversation. As people who have experienced cancer, we know survivorship is not an easy endeavor. We want to think that the completion of treatment leaves us free and clear, solely a reason to celebrate a weight lifted. But it's hard, isn't it? We don't have a doctor, or a nurse always available to address our concerns.

Melissa Rosen:

The issue of longterm side effects and fear of recurrence weighs on us. And we have so much free time. All of a sudden, when treatment ends, all the time it took to get our infusions, to travel to our appointments, all of that time is ours again. It might feel scary. And of course, we've just gone through something traumatic. Every day was just about survival. Many of us didn't have the time, the energy, or that ability to address the larger issues that a diagnosis can bring on.

Melissa Rosen:

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And survivorship is actually often where that processing sometimes begins to occur, because we're not wired to take both physical and emotional hits at the same time. So we lead with the physical, just to survive. We rally for surgery, chemo. And when that physical strain is complete, at least for the time being, it's time for us to address the emotional. But people around us may think, "When it's done, it's done." We may begin to look better, maybe even healthy. We may have more energy. But our outsides don't necessarily match our insides.

Melissa Rosen:

Friends and family think things will return back to normal, but we know the truth. There's a new normal, and still an awful lot to process. We're still dealing with side effects, fears, and we're pulling our lives back together. It takes real effort. Relationships may have transformed, goals may have changed, and our priorities have likely shifted. All this turmoil, this changes, this transition, whatever you want to call it, can impact how we deal with survivorship. And even some basic questions about how we identify ourselves.

Melissa Rosen:

So, are we already survivors? Were we while we were in active treatment? Or do we have to wait five years with no evidence of disease to call ourselves that? What about if we've been diagnosed with metastatic disease, can we even use that word at all? And what about the word survivor? It's a word so many of us are proud to call our own. But for others it doesn't resonate at all. I've heard people use the word "thrifer", the word "warrior", the word "fighter". I've heard people avoid those and say, "Person with cancer." And I've even heard the word "aliver" being used.

Melissa Rosen:

The point is, that survivorship is complicated. And just as with everything, no two people are alike. We have four Sharsheret callers with us today, who have generously agreed to share a bit of themselves with us today. Each one has a very different story. And their stories have impacted their post-treatment lives. Our first speaker is [Yaffa-Leah 00:09:52], who was diagnosed with DCIS, which sometimes known as Stage 0 breast cancer. Yaffa-Leah, welcome and thank you.

Yaffa-Leah:

Thank you Melissa for that introduction. I was diagnosed with breast cancer, almost exactly one year ago. I turned 40 in April. Scheduled my first mammogram, figured it would be routine and in and out. And immediately was suspicious and lead to a very extensive workup. Every time they would do a diagnostic test to look more closely at something of concern, they would find more areas of concern. In the end, I ended up with eight biopsies, three MRIs, and consultations with breast surgeons, plastic surgeons, radiation oncologists, and medical oncologists at two separate cancer centers. I wanted to make sure I was covering my bases. I wanted to make sure everyone was on the same page.

Yaffa-Leah:

So, it took a while, and that's the process I went through for weeks. In the end, it was concluded, pretty much almost unanimously that I had multiple areas in one breast of what was likely DCIS. Although they did say they couldn't guarantee that until they actually got in there and got the full pathology on it. But they also found multiple potentially problematic areas in the other breast. And so they told me that I was likely going to be dealing with this for a while unless I, so to speak, dealt with it all at once.

Yaffa-Leah:

I was given a variety of treatment options to choose from. And anyone who knows me, knows that I'm somewhat of a control freak. And an obsessive planner and researcher, and I have lists out the wazoo. So I agonized. I agonized for weeks on end about what to do. I spoke at length with women who had experienced all of my options. I spent hours on the phone with my doctors. I read medical literature extensively on all the statistics regarding recurrence. I do have a medical background. I used to practice as a PA, and my husband is a physician. So, we felt very comfortable doing a lot of our own research.

Yaffa-Leah:

And ultimately, I chose to have a bilateral mastectomy based on my pathology, and my personal risk factors, and everything that they had found thus far. I chose to go with DIEP flap reconstruction, which is an intense procedure with a longer recovery time. But much better longterm results. So, after many weeks of stress and tears, I finally felt at peace with my plan going forward. That is until I was thrown yet another curve ball. An abdominal angiography that was done in preparation for the DIEP flap, for the first stage of the DIEP flap, showed that I had a venous malformation in my abdomen sitting right on the artery that they would need to grafting as part of the DIEP flap.

Yaffa-Leah:

And this venous malformation is a cluster of blood vessels which put me at great risk of bleeding out on the operating table. And so my surgeons all met for a few hours, one Friday night, and they spoke for a while with each other, and with the radiologists, and looked extensively at the scans. And finally, they concluded that in their 40 plus years of DIEP flap reconstruction experience, they had never seen anything like it. And nobody wanted to touch me with a 10 foot pole.

Yaffa-Leah:

So, they said, "Sorry. Plan is canceled. Back to the drawing board." So three days before my surgery, we changed the plan to implant based reconstruction without grafting. My surgeons also warned me that until they got the results back from the sentinel node biopsy, that they would do at the time of the mastectomy, that they couldn't tell me for sure if I would be officially cured with just surgery. If the nodes were positive, I would definitely need radiation, and 5-10 years of Tamoxifen, a hormone blocker, and possibly chemotherapy.

Yaffa-Leah:

But thank God, the nodes were clear. And my final diagnosis ended up being DCIS, aka Stage 0 cancer. So, in the days following my first surgery, a good friend sent me a gift of a customized key chain that she had made for me. And on one side it had my name, and on the other side, it had a pink ribbon and the word survivor on it. And that was the first time I really thought about the term survivor. I'd been so caught up in the whole diagnostic process and forming the treatment plan, that I was just in the moment, and I really hadn't thought about what came after.

Yaffa-Leah:

And I knew that I was incredibly fortunate that the cancer was found early, and that I was able to be cured by surgery alone. But the key chain got me thinking, was I really a cancer survivor? Did I really earn that term? I didn't have to deal with radiation burns, or fatigue, or suffer through chemo, or lose my hair. I ultimately didn't even have to take Tamoxifen, because of my choice to be extra aggressive

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and remove both breasts. I know countless women who have been diagnosed with breast cancer, and everyone's course of treatment is different.

Yaffa-Leah:

So, how does one earn this title of survivor? Do they only earn it by checking every single box? My cancer was caught before had even invaded the rest of my body, so was I really allowed to call myself a survivor? But eventually, I came to realize that for me, survivorship was twofold. Yes, I did everything in my power to eradicate the cancer that was in my body and survive that medical diagnosis. But I also faced tremendous adversity, and I overcame that. I had the most difficult year of my life as I faced the diagnosis and the rollercoaster that came with it.

Yaffa-Leah:

I navigated my way through an ocean of stress and anxiety. I lost both my breasts, and I'm dealing with the lifelong physical and emotional ramifications that came with that. I've had three major surgeries in the last year. I'm likely facing another one in the fall. I probably will have to have more surgeries as I potentially have to replace my implants every decade. I've had nine months of physical therapy due to complications from scarring. I literally was just discharged from that last Thursday, so suddenly I have all this extra time on my hands.

Yaffa-Leah:

And I'm going to have to be monitored for the rest of my life for recurrence. Cancer created a huge upheaval in my life, and caused me tremendous physical and emotional pain, but I overcame it. I continue to overcome it every day. Yes, I did everything I could to deal with the cancer itself, and close the chapter. But cancer is not a book that can ever be closed permanently. I'll always worry that I'm going to have a recurrence. But I know if that day ever actually does come, I know that the fight will be so much greater. But I know I can do it, because I am a survivor.

Yaffa-Leah:

I have the physical scars to prove my battle and my survivorship. But, I also have the invisible scars, the mental and emotional scarring, and boy, has that mad me tougher. I proved to myself, and I continue to do so, that I can survive. But I'm not just surviving. As Melissa said, I'm thriving. And I plan to continue to do so every day for the rest of my life. Thank you.

Melissa Rosen:

Amazing. Yaffa-Leah, thank you so much for sharing that story. Your ideas about survivorship area really very insightful.

Yaffa-Leah:

Thank you.

Melissa Rosen:

Our second presenter today, is Danielle. Danielle was diagnosed with ovarian cancer recently, and it is at the start of her survivorship experience.

Danielle:

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Hi, thank you. Yes, so I was diagnosed in March, or actually February of 2020, and then had my surgery March 16th, right at the start of COVID. And went through six rounds of Carbo and Taxol. And I completely my six rounds in August. For me, at that point of time, it was like I was diagnosed. It was like surgery, let's just do it, do it surgery, get through chemo, like I could do this. Let me just make it to the end of chemo, and everything's going to be okay. Except that once I got my last day of chemo, I was expecting to feel like this enlightenment of, okay I can go on with the rest of my life. But it wasn't like that.

Danielle:

As Melissa was saying in the beginning, and I really connect with that, is that I was pushing, pushing, pushing, and I just kept wanting to get to the next step that I wasn't going or processing any of what that actually meant. So then, after chemo, I had to deal with the emotional side of things. And for me, everyone said, "You know what? It's harder than chemo." After chemo, it's harder, and I kept saying, "I just don't believe you." How could not be. Chemo was so hard, and so devastating on your emotional and physical being. But now, once going through that, I understood what they meant.

Danielle:

I had to kind of deal with what it all meant. I had all these unresolved feelings of will this come back? When will it come back? How much time do I have? And you don't trust your body. Every little ache or every little pain, you think the cancer's coming back. And it's this constant feeling everyday you wake up, and you're like, think about it. It's hard not to. So then, thinking about the idea of survivorship, and what it means really kind of confused me. And I had a lot of trouble identifying with it.

Danielle:

Because I was thinking to myself, have I really survived cancer? I feel like I'm kind of like in this holding pattern of wait and see. So, I'm not sure if this really feels like I've survived cancer. I'm in the moment. And then I'm thinking, am I cancer thriver? To me someone who is thriving is someone who is growing. And then think to myself, well maybe I'm growing as a person, through this experience. I don't know.

Danielle:

I envision someone who is thriver as someone who is getting stronger emotionally and physically. And I'm thinking that maybe I'm a little bit too close to the anxiety of all that kind of cancer and treatment brings. And that maybe with time, I can call myself a survivor or a thriver. But for right now, I kind of see it as I take it day by day, blood test to blood test, scan to scan. And just trying to make myself stronger physically and emotionally. But for now, I feel like I'm just kind of at the start of what we call this as our cancer journey. So that is where I am.

Melissa Rosen:

Danielle-

Danielle:

Thank you.

Melissa Rosen:

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... thank you so much for sharing. Sometimes when you're so close, it's a little hard to do. But clearly you've given this some thought and have some real insight to it. So thank you for sharing your story. Okay, I know with each of my cancer experiences that it was incredibly comforting and almost empowering even to hear other's stories. It can sometimes even help us process our own experiences. But it can't be the only thing we rely on to do so.

Melissa Rosen:

So, before we hear thoughts from additional callers, we have a unique opportunity. Joining us today from Tel Aviv is Kayla Rosen. Kayla is a social worker, a Jewish meditation guide, and a holistic therapist. She is joining us today to share some ideas on how we frame our cancer experiences once we've entered that period that we sometimes call survivorship. Kayla will speak briefly and provide us with the tools, or all the tools except for the pen and paper to spend a short four to five minutes doing some free-flowing writing.

Melissa Rosen:

One note though before I turn it over to her. If you're not comfortable for whatever reason, writing, please take the next few moments to think about the ideas that Kayla presents. And after the writing, we will join back together to finish this very important conversation. Kayla, the screen is yours.

Kayla Rosen:

Amazing, thank you so much, Melissa. Thank you so much for having me and being here. It's really an honor to be a part and among so many strong, and brave, and powerful women. And as Melissa, and as Yaffa-Leah, and Danielle all spoke about survivorship, the identity of survivorship is obviously extremely complex and nuanced. And we are going to go into a journaling exercise to dive in a little bit more into that.

Kayla Rosen:

But let's take a step back, and look at identity in general as a human. As humans, our sense of self is always expanding. We are developing parts of ourselves. We are taking new titles, new identities. And every day, when external things happen to us, and internal changes happen to us, we are adding in new things and creating new parts of our identities, and we're also getting rid of old things that don't align with us anymore.

Kayla Rosen:

And often, from day to day, we're actually flowing in and out of different parts of ourselves, or different identities within ourselves. And our sense of self is so dynamic, it's flowing, it's changing. And it should be, it's actually what makes us human. A single person is comprised of so many inner parts, each with different titles, different emotions, different thoughts. And sometimes these different parts can actually be really opposing one another, almost contradictory.

Kayla Rosen:

We may feel rage and love at the same time, or hope and fear. One part of us might be telling us to do something whole heartedly, and other part might be screaming at us, telling us do not do that. But these are the moving parts of our inner world. And it's so important to acknowledge how natural this is, how this is exactly what makes us human. And more so, we should actually celebrate it.

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Kayla Rosen:

But often, for every human being, what happens at certain points, is when we encounter parts of ourselves that don't seem to fit in with who we think we are, we often reject them. We learn to push them away, run away from them. Sometimes a new part, or a new emotion, or identity can bring up feelings that are pretty uncomfortable and we don't want to sit with, we don't want to face.

Kayla Rosen:

Sometimes a new part of us contradicts what we previously thought we are, and that's really hard for us to integrate and bring in, because as humans, we really like things to be crisp, clear, and clean. We love the simplicity of black and white. We love being able to say, "I am this. And I am not that." It's easier, it's simple. But I want to challenge that for a moment. And I want to ask ourselves, what if we were all of it? Just as we can be a mother and a daughter simultaneously, a friend and an employee at the same time, a patient and a thriver. What if we can be all of those simultaneously, and let them coexist within us?

Kayla Rosen:

Because, they're all equally true at the same time. What if you could let yourself be a patient, a survivor, a fighter, and also a thriver? What if you could let yourself be a cancer patient, and a mother, and a partner, and a friend, all at once? What if we gave ourselves permission to be, all of us, to express each and every part that needs to be seen and heard. And so instead of choosing one, we can learn to take every single part and integrate it, and allow it to become part of who we are.

Kayla Rosen:

And take it in as part of yourself, and that's actually how we become whole. That's how we become that full person, that full sense of self. When we take each part, the beautiful and the ugly, when we take the fearless and the fearful, and we fully accept and love each part. And when we step into this wholeness, it's actually where we find our strength. We're able to stand really sturdy on who are, because every part of us has a space to be heard, the space to be seen, and accepted and loved, no matter how painful, no matter how dark, no matter how amazing it is.

Kayla Rosen:

Because every part of us deserves a place to be seen. Every part of us is us. And it's in this space of strength, and wholeness that we actually begin to heal. Because we are taking the different parts of ourselves, and we are learning how to integrate them into our full sense of self, whole self. We no longer have to spend energy hiding, running away, pushing away parts that might feel uncomfortable. It might be difficult to bring them in, it might be painful, but we're learning to love and accept every aspect of ourself. And we do find so much strength and healing in that. And we need to learn to celebrate that.

Kayla Rosen:

So, we're going to go into a journaling exercise right now, because one way that we can actually learn how to integrate these parts and love every part is by creating a dialogue with the different parts inside of us, and starting a conversation. So, we're going to do that right now with writing. So, if you feel comfortable, you can close your eyes for a few seconds, or leave them open, and just think. Think to yourselves about a part of yourself that might be a little bit difficult to accept. A part that maybe you have been putting off to the side.

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Kayla Rosen:

It could be an emotion, a specific emotion, or a title. It could be another version of yourself, whether at a different age, or in a different experience in life. So take a moment to find that part of you. And, we're going to go into this journaling exercise for around five minutes. And we're going to be writing letters. So we have two options. You can choose one, and maybe save one for later. Or if you can get both done now. The first option is writing a letter from this part of yourself. This part that maybe is a little bit on the outside, a little bit not seen, a little bit not heard.

Kayla Rosen:

This part can write a letter to you. What does she have to say to you? How does she feel? Who is she? What's her name? Just give her space to talk to you. So who she is. And the other option is writing a letter from yourself to this part of you. What do you have to say to her? How can you love her just a little bit more? So we're going to take five minutes now to do that.

Melissa Rosen:

Thank you so much Kayla. I will give you a one minute warning, but when we're winding down. But please take some time to either think or write about some of the really intriguing things that Kayla has presented.

Melissa Rosen:

(silence)

Melissa Rosen:

We have just over one more minute.

Melissa Rosen:

Okay, finish the thought you're working on. Wow. That was amazing. I wrote too, and was actually surprised at what came from my pen. For those interested, Kayla will share one more writing prompt at the end of the webinar. So once we conclude, if this is something you found useful, you will have the opportunity to continue. I want to introduce the next caller. Henrietta was diagnosed with breast cancer 30 years ago. She has had a lot of time to hone her thoughts on survivorship. Henrietta, welcome.

Henrietta:

Thank you, Melissa. I think I'm unmuted.

Melissa Rosen:

You're good.

Henrietta:

Right. As Melissa said, I am a 32 year survivor. And as everybody else has said earlier, what does the word survivor mean? To me, it means I came through whatever the illness or crisis was, and I'm here to fight another day, and perhaps even another crisis. When I was diagnosed, I was age 47. The concept and practice of breast removal with immediate reconstruction had just begun. It did not exist like it exists now.

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Henrietta:

I was advised against that procedure by my general surgeon. He said, "Too much surgery at one time." I wish I had chosen that route, and I would recommend that to anyone who's considering it now, since I ultimately went through at least five surgeries to get to the same result. Instead, I had a modified radical mastectomy on December 15, 1989. And in 1990, I had a prophylactic mastectomy of the left breast. I chose chemo over radiation, and lumpectomy because I did not want the risk of lymphoedema in my dominant right arm.

Henrietta:

Like Yaffa-Leah, I was not a PA, but I have worked in the medical system for my entire career. I'm a speech language pathologist. And we deal with cancer head and neck, so was enough familiar with some of the consequences and the unintended consequences of both chemo and radiation. I did not want the lymphoedema because it would have been in my dominant right arm. And do everything with that arm.

Henrietta:

What I want to share, is what it felt like when I finished my chemo therapy sessions. My chemo was given once per month for six months. It was very disruptive to my working and daily life, because of the Ativan they gave to halt the nausea. I figured out how to deal with all of that, and I got through the six months as best as possible. What I didn't expect were the reactions that I had after those six months had passed. I remember sitting in my office all alone, feeling very frightened and sad.

Henrietta:

While I was going through the chemo, I fortified myself to get through it. And it felt like I was fighting against the cancer. Now, how was I going to get through the anxiety of waiting five years to see if this was going to return? When I would go back to my oncologist, I would not even let him say hello until he read the numbers off of the three cancer tests. Every time something would come up, pains or bumps, etc. the fear would return. I had pain in my left lower back, somewhere in 1992. So I went for an MRI.

Henrietta:

And the orthopedist said something appeared in the liver, and my current oncologist was ready to send me to the Moffitt Cancer Center for a bone marrow transplant. He was certain I was a goner. Instead, I chose to switch to a different oncologist. Second oncologist asked, "If you have metastatic..." Okay. Someone else say it.

Melissa Rosen:

Metastatic.

Henrietta:

"Metastatic cancer to the liver, how come your liver tests have been normal for the past four years?" This was an obvious question, but not to the first doctor. And I will share something I didn't write here. I remember when this diagnosis came up, I sat down in the middle of my king size bed. I look up at the ceiling, and I said, "God, I know there's a lesson in here somewhere. But could I please have one semester off." Okay. The journey of breast cancer recovery is marked with lots of trauma and not all of it is physical.

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Henrietta:

As Kayla has said, as Dana has said, there is an emotional toll that impacts you as a patient. Not only you, but your family, and everyone who's connected to you. You begin to look at life in a different way. You have come face to face with a life threatening illness. It is about the most serious trauma you can deal with, except for the loss, the death of someone very dear to you.

Henrietta:

Don't ignore the emotional impact. Acknowledge it, seek out ways to cope with it. In my opinion, it is ever more important than the physical impact. In current times, we understand that mind and body are strongly connected, and that your mood, sense of wellbeing, and faith in return to good health, impacts your physical recovery. I was fortunate. I had an excellent role model in my mother who had survived a difficult journey through cervical cancer at age 45. I was all of six years old.

Henrietta:

While in the hospital, she dreamt that the angel of death was at her bedside. She pointed her finger at him and said, "You go away, I have two children to raise." And he went away. She survived that cancer, and then she had another one at age 67, because she had so many radiation treatments in the pelvic area for the cervical cancer that she then developed cancer of the sigmoid colon. Well, I was pregnant with my first child, and she was not going to miss that one.

Henrietta:

As I said above, I am now 32 years of survival. Every five years I send a card to my general surgeon to let him know I'm still on the planet. I no longer think of myself as a cancer patient. I have been blessed not to have any [metastacysts 00:42:52]. But I do consider myself a survivor, someone who's come through a very traumatic, physical and mental crisis strong enough to move on with my life. What I learned as a cancer patient and survivor has helped me deal with other crises in my life, and has also made me a better speech language pathologist because I can understand things from a patient's side as I treat patients.

Henrietta:

As an after comment, my cancer treatment was in '89, my initial. And in '98, I had a triple bypass. And I'm still here. If I could get through the cancer journey to a place of survival, I can get through most anything else. That's it

Melissa Rosen:

Henrietta, thank you so much. That was an empowering message. I love it. Thank you. So finally, our last speaker, Ann, was diagnosed recently with de novo breast cancer. De novo means that at the time of the diagnosis, her cancer had already spread and was metastatic. We learned right before we went live today, that Ann, can't be with us because she had a medical issue that needed to be address. And that really is the perfect example of the roller coaster that survivorship can bring.

Melissa Rosen:

I think that some of the things that we think about when we think about the term survivor with regard to those who are facing metastatic disease, is it's complicated. It's an ongoing experience. And sure

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there are many times in that experience that people's lives go on as planned, and then maybe they'll have to step back out for some additional treatment before they can reenter life.

Melissa Rosen:

And so, for some, in that situation, the word survivor doesn't feel right to them. Thriver is a word that's commonly used for people using metastatic disease. But others, like I said, we're all different, and others do really embrace the term survivor. But what Henrietta said, is very relevant here. If I can make it through that first experience, I can make it through. So, I just want to say one more time how meaningful it has been to hear what are callers have shared. Thank you so much for your willingness.

Melissa Rosen:

It is clear that while cancer is an experience that often has us feeling like we've lost control, words can help shape our experience. And choosing words that resonate with us, can help us take back some of that control. And I think that from what we've heard today that is very clear. We do have some time to take questions. If anybody has questions they'd like to put into the chat box, but we did get a few ahead of time that I'd like to share with you.

Melissa Rosen:

One of them was actually not from someone who had dealt with cancer, but from a healthcare professional, and wanted to know the implication for mental health professionals for those treating survivors. I love that this question came in, because it meant that there are doctors and mental health professionals and all sorts of people in the field of oncology and health care in general that are working to enhance support for cancer survivors. And the one thing I would say is that it's easy to turn your attention to people who may need more help, maybe those who are in active treatment.

Melissa Rosen:

But simply to remember that those making the transition away from active treatment are really at a complex point, and need support as much as ever, if perhaps not more. And also, that survivorship and healing is not linear, and so while somebody may appear to be doing well for months, and even years, there could be a point where they might need extra support. I also want to point out to all the health care professionals who may be joining us today, that Sharsheret has a survivorship training that address these kind of things, specifically for health care professionals. And we are offering it on August 3rd. If you've signed up for this, you'll be on our mailing list, and you'll get information about that specifically.

Melissa Rosen:

Somebody asked, "Do you consider your date, the date you got your diagnosis, the date you had your surgery, or the date you finished, your survivorship date?" And I think the great news here is, we get to chose. One of the things that used to be, was that survivorship was officially commenced five years after you've completed treatment and had no evidence of disease. But, there's a much more modern and inclusive definition that the National Coalition of Cancer Survivors has put forth, and that is generally accepted among health care providers, which is anybody who's been impacted by cancer, whether they're in the diagnostic process, in treatment, post treatment, in between treatments, can consider themselves a survivor. And so you get to chose what feels right to you. And I think that that is very important, and very empowering.

Melissa Rosen:

Re-defining Life After a Cancer Diagnosis: Why “Survivorship” is Such a Tricky Word

Okay, time for just one or two more questions. One of the questions was about, somebody actually shared, and I think this is really what was here, spoken about today. "When I think of the term survivor, I feel like a battle is won. When I think of the word thrive, I feel like someone is doing very well. But if you have a cancer that's metastasized, and for the moment, doesn't have a cure, I think of that as being a warrior." And the person who asked this question wants to know if that's how the medical field defines our conditions, or is it just survivor or patient.

Melissa Rosen:

And my answer to that is it doesn't matter what the terms are within the medical profession. Sometimes, healthcare professionals use words simply because that's what's been used in the past. And from speaking to people, and knowing myself, some of those words can even be dehumanizing, or feel dehumanizing. But when talking about ourselves, we use words that resonant with us, that empower us. It doesn't matter what anyone else uses.

Melissa Rosen:

There were many other questions. I see some are coming in here that I want to take a quick look and pick one from here. But, we will try and reach out to anyone who asked a question and get back to them. So, actually, Suzette, thank you for this comment. She says that her own issue with the word survivor is personal as she is the daughter of a holocaust survivor. And she was able to deal with her cancer by remembering that her father survived Auschwitz. So, yes, within the Jewish community specifically, survivor very often takes on a completely different meaning in relation to the holocaust.

Melissa Rosen:

And while people are dealing with something as difficult as cancer, it could be that that's not something they even want a reminder of, another difficult collective experience. Or it could be one gains strength from it. So that definitely resonates. Again, there were many more things, and we're going to get back to everybody who asked a question, whether ahead of time, or through the chat box.

Melissa Rosen:

But for now, I want to thank Kayla Rosen for her fascinating insights, and to our callers for sharing their thoughts and experiences. I found this conversation fascinating, and as a survivor myself, really thought provoking. And I hope you did as well. Once again, I want to thank our wonderful program partners on this important webinar, Cancer Support Communities, Gilda's Clubs, Barbells For Boobs, and Life Well Lived.

Melissa Rosen:

And I want to recognize their shared goals and working together to support all those impacted by cancer. I want to thank our generous sponsors Merck, Novartis, and CGEN. And I want to thank all of you. All of the women and all of the men who have joined us today. Our conversation really focused on breast and ovarian cancer, because that's what Sharsheret focuses on. But the realities this conversation could have been, can be, will be, because of the recording, relevant to many other cancers, whether [inaudible 00:52:30] related cancers that we often talk about, or other cancers entirely. That's important to keep in mind.

Melissa Rosen:

Re-defining Life After a Cancer Diagnosis: Why “Survivorship” is Such a Tricky Word

Please take a moment to answer a poll on your screen. This is our evaluation, to fill out the brief evaluation survey that's linked in your chat box, or right there, right now. The evaluation provides the opportunity to request support, to request one of our free Thriving Again Kits, or other resources. It asks about your interest in future topics related to survivorship. You can click that link now, and still hear the end. One of the last things I want to do is invite Kayla back for a brief moment to share one final writing prompt for those of you are interested in continuing writing.

Melissa Rosen:

The prompt will also be placed in the chat box. Kayla can you join us, again? Screen is yours.

Kayla Rosen:

Okay, hi. Thank you Melissa. So, as we took the time to connect to another part of ourself, and just kind of give that part space to be seen and heard. I want to take the opportunity to continue this. And everyone can ask themselves what is one thing that I can do to honor this part of myself, this week, today? And that could look very different for everyone. It could be sitting for five minutes, and letting that part of you cry. It could be letting that part of you be angry. It could be taking a hot bath, or going for a walk in nature, sitting by the beach, or whatever makes you feel calm.

Kayla Rosen:

And it could simply be just talking to that part of yourself, listening to it, taking some paper and just free writing, listening to what this part has to say. And so, if you'd like, you can just take a moment right now and write it down actually. And let that, this writing down be a commitment to yourself. Let the words that you write set the intention of really honoring yourself just a little bit more today, week, this year. Thank you.

Melissa Rosen:

Amazing. Thank you. As we conclude, I want to remind you that Sharsheret is here for you and your loved ones during this experience, during this time. And we provide one on one support, and programs designed to help navigate all aspects of the cancer experience. All are completely free and completely confidential. You can also email us at ClinicalStaff@Sharesheret.org. And finally, I want to let you know that we have several exciting webinars on a wide range of topics planned over the next few months. But later in June, we have two specific ones. We're offering a webinar on pregnancy, breast feeding, and breast cancer. And another one on mindful breathing for stress and pain reduction. Please check out our website regularly to see what topics are coming up. And with that, I want to thank you all again for joining us, and have a wonderful day.

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

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