Beyond the Diagnosis:
Coping with Anxiety and Depression

National Webinar Transcript

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Melissa Rosen:

Welcome, and thank you for joining us. I'm Melissa Rosen, Sharsheret's Director of Training and Education. This evening's topic Beyond the Diagnosis: Coping with Anxiety and Depression is an important one. You've likely heard me say before that cancer is much more than a physical experience, and tonight we're going to explore the emotional experience that frequently accompanies cancer.

Before we begin, I want to take a moment to thank our sponsors for the program, Psychiatric Family Care LLC, Merck, Novartis, and the Cooperative Agreement 24-0061 of the Centers for Disease Control and Prevention. Tonight's webinar is being recorded and will be posted on Sharsheret's website along with a transcript. Participants faces and names will not be in the recording. Still, if you'd like to remain private today, you have the option to turn off your video and rename yourself, or you can call in to the webinar. Instructions are in the chat box now for both options.

Additionally, we also have closed captioning available. To display live captions on the bottom bar, click captions and then show captions. You may have noticed you were muted upon entering the Zoom. Please stay muted during the call. We've received a large number of questions during the registration process, but if questions arise during the presentation, please type them into the chat box. We'll be monitoring it and we'll do our best to include them in the Q&A at the end of the session. I do want to point out that there will be a great number of questions and we're going to do our best to answer as many as possible, but I'm just noting right now that we cannot answer any questions that regard somebody's specific medical condition or requesting medical advice.

Along the same lines, I want to remind you that Sharsheret is a national not-for-profit cancer support and education organization and does not provide any medical advice or perform any medical procedures. The information provided by Sharsheret and tonight's speakers is not a substitute for medical advice or treatment for specific medical conditions. You should not use this information to diagnose or treat a health problem. As always, if you have any questions that are specific to your situation, seek the advice of your physician or qualified healthcare provider.

Before we welcome our guest speaker to the screen, we are so happy to have Kerith with us. Kerith is a Sharsheret caller who will share her experience with cancer and anxiety. Kerith, thank you so much for being here.

Kerith:

So I'll start, and I know everybody's story is different. I'll just give you a short piece of mine, which was, I will always, probably the rest of my life, remember the call that came with the initial diagnosis. I burst into tears. I immediately thought I was going to die and feeling very alone. It was a very rough week, because that same week, we were planning to tell my children that we were getting divorced. So anxiety was already quite high for me and then just off the charts at that point. And then I realized as they asked me to share tonight that anxiety was really with me each stage of my cancer journey. Right after the diagnosis, it was as many of you I'm sure experienced, there's not a lot of time to process or wallow. It's right away you have to start making decisions, find doctors, get second opinions and figure out what's the right treatment.

And I really describe that time as mental anguish because I kind of felt like this was a life or death decision I was making. And I think in these cases, they really are often those types of decisions. In the end, a dear friend of mine, she also had had about with breast cancer, and she said to me, "If you can reduce your future risk as low as possible, wouldn't you want that?" And she also knew how anxious of a person I was. And so deep scanning and things like that probably would not be a good choice for someone like me. So for me, that became my choice, whatever I need to do to make my risk as low as possible. And so initially having made the decision, sure, you got a little calm because that piece of the intensity was over and then it became really fear and it was for me fear of all the unknown.

I hadn't really known anyone who had gone through this before. I don't know how I managed to make it to my age in life like that. So everything was new to me. What's the recovery going to be like? What are the surgeries going to be like, the treatments? How am I going to look? Which let's not... You don't want to belittle that point. It's pretty major, at least it was for me, so much to be anxious about. And then I was also working my full-time job, thankfully from home and trying to keep strong and positive for my kids. So I'll just share a few things that helped me along the way with my anxiety. One was trusting the doctors I chose. Once I made the choice, I had to really just, they're the experts, two, speaking with women who had been through it before. And Bonnie, who's on the call today, and Sharsheret was instrumental in that.

I spoke to a number of women who are part of Sharsheret who helped me and they really helped me with, to be honest, here's what you're going to experience and what you might feel. Also telling people in my life, I didn't open up immediately. And finally, when I opened up and told people what I was going through, I was amazed at how many other people either had gone through it themselves and I had no idea or friends or loved ones of theirs. I think one of the very important things I learned was it's okay to say that you're not okay when people ask, and that doesn't come easily, I'm sure and I know, but it's important. And then I wrote therapy in my notes with all caps. I had a therapist, I had a personal therapist. I had one through my oncologist's office at Sloan.

Those were both covered by insurance. I also spoke to Bonnie from Sharsheret a whole lot. And some people might think that was overkill, that's three people. But I found that each person kind of helped me from a different perspective, one, and two, I just feel like take all the help you can get. It really did help keep me strong. And sometimes just sharing my anxiety and saying how I was feeling was what I needed to keep moving forward. I wrote a daily gratitude journal, and I think what's really important is recognizing the small wins. And I remember wins could be literally like I managed to stand up off the couch, not even go anywhere. So really small. And I will be forthcoming that I am an anxious person in general. So I was already on a low dose of an anti-anxiety medicine, which I was thankfully able to stay on through all of my surgeries and treatments.

So I would just say, if you're not on it and you feel like you might need it, you should talk to your doctor and just find out. And again, no professional medical advice, just always asking a doctor and making sure you can have whatever you need at your avail. And then I think the best and last piece of advice, what worked best for me was yes, I took the time, I was scared, I cried and I said, "Why me?" And just when those times happened, I realized that's not a really productive, helpful way to move forward. So I forced myself to move the why me to how am I going to get through this? And in the end, that's what helped me get through it. I do want to note that everyone has their own journey, their particular fears and anxieties. I'm still an anxious person, so I am looking forward to learning from this webinar as well. I just thank you for allowing me to share a bit of my story tonight.

Melissa Rosen:

Kerith, thank you so much for opening up to us and sharing your experience. I think one of the things we'll hear tonight is this is so normal and part of the cancer experience, but having people talk about it really normalizes it. So thank you so very much. Okay. All right. So we are so honored to have with us tonight Dr. Elizabeth Malkin with us tonight. She has a doctorate in psychology and is an MSCP, is a neuropsychology fellow at Memorial Sloan Kettering Cancer Center. She currently works with oncology, hematology and transplant patients during treatment and survivorship across the lifespan. She completed her doctoral internship at Rusk Rehabilitation, NYU Langone Health, working with the adult outpatient service as well as the inpatient adult neuro rehabilitation and cardiac and complex medical condition services. She enjoys writing and publishing blogs and articles specifically in the areas of leadership and resilience. I'm so happy to welcome her to the screen right now.

Elizabeth Malkin:

Thank you so much, Melissa, for that wonderful introduction. Hi everyone. It's truly an honor to be here with all of you. This is a group of people that is not only important to me personally, but also professionally. I do this every single day and I really don't think that there's any better way to give back than to help people with their diagnoses and what comes after. So I'm excited today to talk to you all about how to manage depression, anxiety, and also neurocognitive effects. So I'm going to go ahead and share my screen. Give me just one second. I'll just share it first and then share the PowerPoint.

Elizabeth Malkin:

I am a neuropsychology fellow, so in addition, I'm a psychologist first, but I also deal with a lot of the neurocognitive effects that individuals go through after the diagnosis, going through treatment and in survivorship. And I think it's very important to address and understand that aspect as well and how that can affect anxiety and depression. So I'm going to talk about both or I guess all three today. So at the end of this, I want people to have a better understanding of what the psychological impact is on cancer patients. Oh, sorry, it's anxiety and depression, but there's also, it's on a spectrum and every day there's different challenges that you're presented with. So we want to talk about that a bit today. Also, understanding that there are changes in neurocognitive functioning at diagnosis, treatment and in survivorship. And that does have an impact on your mental health. It's a bidirectional relationship. So I'm going to talk a bit about that.

I want to talk about effective interventions and things that you can look for in your treatment and your therapy afterwards. So just this way, it'll give you some information as to what to look for or what kind of providers to look for and to ask them questions of do you provide this kind of treatment or this kind of intervention. And so just to give you some tools and understanding there. And also, I have a list at the end of resources and some professional support options, some websites and things like that that are included in the last slide. But I believe that can also be, well, you'll have the recording, but I'm not sure if maybe that list will be sent out as well. So you'll have that. So the first thing that I'm going to talk about is the mental health impact of the diagnosis, treatment and also survivorship. So it's really important to note that there is a high prevalence of depression and anxiety with cancer patients.

So depression and anxiety is the most common in terms of psychological issues across all stages and all sites. Also, pertinent to this population, half of women with early stage breast cancer experience clinically significant anxiety and depression at diagnosis. So it's not even, maybe the treatment hasn't begun, maybe it's not survivorship yet, just right at diagnosis, which makes a lot of sense. You're kind of hit with a ton of bricks with the diagnosis and makes sense to feel that way. Ovarian cancer patients also have a high burden in terms of mental health issues. So these are things that patients are dealing with and it's underrecognized in oncology settings, because when you go through treatment, the goal initially, the main goal is just to get you better. If there's something physically wrong with you, you go to a doctor, they go through treatment, they try to fix it for you, but people don't always pay as much attention to the mental health impact. And you fix mental health issues the same way.

It's something that is uncharacteristic. It's not something that might be normal, but it's not necessarily wrong with you, it's just what you're going through. It's the situation that you've been dealt and it's underrecognized because everything else is happening that takes a backseat. So it's really important to note that you want to monitor how you're feeling and you want to speak up with your providers and your clinicians because you want them to know that you need some extra help in addition to just the physical treatment. So it's important to talk about quality of life and outcomes when it comes to cancer treatment. Depression and anxiety while you're going through treatment and survivorship can cause significant distress and disability. It lowers quality of life and actually can worsen physical symptoms. So there's a very strong mind-body connection. And so how you're feeling is going to impact how you adhere to treatment, to medication, whether you want to get up and do things throughout the day, whether you want to seek support from your family or friends or loved ones.

So it's actually linked to poor prognosis, if it's not something that's treated or not something that's recognized when you're going through treatment. Depression is actually associated with 24% higher risk of cancer recurrence. And that is because adherence is really impacted when it comes to treatment. So it makes a difference when you have help and you have support and you want to get up and do the things that your medical team wants you to do because it's really difficult to just in those moments kind of disconnect and not want to engage in your treatment. And so that's why this is so important. It goes hand in hand. Anxiety is also correlated with increased recurrence though to a lesser degree. So we're going to talk a bit about that as well. Specific to breast and ovarian cancer, with breast cancer, there is a lot of distress around fear of recurrence and happening again and also body image issues.

Also, for younger breast cancer survivors, they have a higher risk for depression, because when you get into survivorship, you have this longer runway, which is wonderful in terms of living your life and doing all the things you want to do. But now, it's also creates extra time for worry and being conscious of, could this happen again? When might this happen again? And so that's why there's a higher risk of depression. And for ovarian cancer, same thing. Patients have a three-fold, greater than a three-fold higher risk of being diagnosed with mental illness. Typically, that's depression, anxiety or adjustment disorder. Adjustment disorder, it's like you've been dealt certain news and you're dealing with it within six months. It's not maybe something that'll stay past that, but you're adjusting to the reality of the situation. So that's within two years post-diagnosis compared to the general population.

And now, I want to talk about some neurocognitive effects and how that impacts anxiety and depression. Now, that we've laid the groundwork of why it's really important to talk about this stuff. So there are cancer related cognitive, or there is cancer related cognitive impairment, it's like buzzword I feel at times, but chemo brain or chemo fog is often linked to chemotherapy and it's a real thing. It's not just a little thing that, oh, I'm just impacted and it's just now and it's not going to impact my life going forward. Actually, a third to a half of patients experience persistent cognitive difficulties, and that includes memory lapses, difficulty with attention and concentration, executive functioning difficulties. We'll go into what these are in a little bit, but I just want to highlight them. Processing speed is slower, and so often anxiety we think is worrying, excessive worry, but it can be conflated with issues with attention and concentration and also memory. If you're feeling like your memory is lapsing, that's very worrisome for a lot of people. That produces more anxiety. There's a higher chance of that.

And also with attention, same thing if your mind is preoccupied with worrying about medical things or just life things or family things, then you're going to have issues with attention concentration. We don't quite always think about these things going hand in hand, but it's hard to tease out what exactly is just anxiety or attention concentration or even memory lapses. So that's why it's important to talk about this stuff. 30 to 50% of patients with non-central nervous system cancer, so non-related to the brain or your spine, still show measurable cognitive deficits at diagnosis, right at diagnosis, even pre-treatment so pre-chemotherapy. And that's because it's the cancer itself. It could be the inflammation, the stress, that can all actually impair your cognition even prior to therapy. And there's also this reduced self-efficacy. When you have these issues with memory or attention or executive functioning, you start to trust yourself less. And that also starts to create more of an increase in depression and anxiety as well.

So what is the impact of these negative effects due to chemotherapy? So there's a negative impact on daily functioning and the quality of life for survivors. It actually increases your chances of developing depression and anxiety, and these are the domains that are impacted. I'm going to talk a little bit more about each, but when we talk about memory, we're thinking about short-term and maybe long-term memory. Long-term memory is thinking about birthdays and dates that are important to us or events in our life that are important. But short-term memory is thinking about like, oh, what did I eat a few days ago? Or what did somebody say to me even a couple of hours ago? And working memory is that part of your brain where somebody gives you a piece of information, they're asking you a question. So you have to take that information, manipulate it in your mind and give it back in a different form.

So that actually declines when you are going through cancer related treatment. You have increased forgetfulness and difficulty learning new information. And this is important to know, because again, this creates the sense of, oh, I'm not trusting myself. What are others thinking of me? I can't even come up with a word or I can't remember something that somebody told me. We start to get very self-conscious, and that increases anxiety. It also increases depression because we start to feel like there's something really wrong with us in addition to just the physical stuff. Now, we feel like we're losing our mind in a way. So that's why it's really important to know that these are possible symptoms to look out for cognitively as well. Also, with attention and processing speed, they're slowed thinking. There's more difficulty with concentrating, and these are actually somatic symptoms of depression. Oftentimes when you're in the hospital, they're going to give you this thing called a PHQ-9, and that's a depression symptom questionnaire.

And a lot of the symptoms are actually somatic. They're physical symptoms. And so it's important to know that if these things are happening, that it could be a sign of depression. It could also just be a sign that there is some cognitive deficit going on, and they might be both happening. They can go hand in hand. Executive function is more of those higher order cognitive skills like planning, organization, problem solving, decision making. When a diagnosis happens and you're going through treatment, all of that stuff becomes much harder for many reasons, because A, your mind is occupied just mentally with what's going on. Your body is changing physically, so that's impacting the way that your mind is working. And also, you're not operating at 100% at that point. And I think one thing, especially I see with women, and I deal with people with a lot of different, they've maybe like somebody had a concussion or even with transplant, right?

People, it's really hard to accept for women that they can't operate at a 100%. And oftentimes many of us are operating at a 100%, if not 110%. We are maxed out in our lives and we're maxed out mentally. So when something happens that sets back your body and your body's telling you, I can't operate at that level, it becomes really difficult for us to accept that I can't do all of the things and manage the family and manage my job and all of the things that I was doing when I wasn't diagnosed with an illness. So I always suggest to patients, and I always encourage them to leave a buffer in your life so that you're not operating at 100% every single day so that if something happens, or if you're having a bad day, you have a bit of a buffer, you leave yourself some room to breathe.

So that's just something to consider. And men too deal with this as well, but I often see women take on a lot more in terms of just what their bandwidth is. They'll just take on more than that. Also, verbal fluency and word finding difficulties. This happens really often where it's like on your tongue, you're thinking of a word but you can't remember it. That kind of chemofog that I was talking about earlier, that can actually gradually improve after treatment, but it's very concerning for patients while it's happening. If you're trying to retrieve a certain word, you're trying to express a feeling and you can't quite come up with that word. That's very distressing. So that's another thing that I tell people to look out for in terms of cognitive symptoms. The other thing too, that can help with lessening the burden cognitively for us is cognitive reserves. So what does that mean? That's if you have more education, maybe you're a big reader, you give yourself a baseline that's a little bit higher. Again, it's a buffer.

You're creating a buffer that when these things are happening and your body and mind is impacted, you have some more runway. So that's why we always, one thing I do as neuropsychologist is baseline testing with people to see where they're at so that when we test, again, they might be in the average range, but for them, it could be a relative big change because maybe prior to that, they were operating in the high average or even superior range. So that's just something to think about. What is your cognitive reserve in those situations? So why is this important? There are many links between cognitive effects, anxiety and depression. Neurocognitive effects, they do not occur in isolation. They're very much intertwined with mental health, and it's also a bidirectional relationship. So not only are things happening to you physically, but things are happening to you mentally, and it's impacting the way that your mind is working not just on a physical level, but also a mental, emotional and cognitive level.

So higher cognitive difficulties can actually increase levels of depression and anxiety and vice versa. You can feel forgetful or be unable to concentrate often, and that will, again, lead to greater anxiety or more feeling down. So these things are exacerbated when you're going through treatment. So that's important to know. Anxiety impacts attention and working memory. So if you're preoccupied, again, as I was saying, if you're worried, if you have a lot on your mind, you're going through your medical treatment. If somebody's talking to you or saying something, it's really hard to be preoccupied internally and also answer to somebody. And people get frustrated sometimes even your family or your friends, they're like, "Oh, aren't you listening? Did you hear what I said?" But it's not that you might have an issue with attention at all, it's just that you're preoccupied and the anxiety is really there for you.

Also, depression can slow information processing. So depression, a lot of times it just slows down everything in terms of mental processing. So if somebody's talking to you even and telling you something, it might take you a little bit more to register what they're saying. You might need to hear something a few more times. And so oftentimes it's just nice to let your family members know, your support system know like, "Hey, I am here and I'm listening, but sometimes you have to repeat things, you have to tell me things a few times," it's information overload because you're taking on so much in terms of medical information, maybe you're still trying to manage aspects of your life. And so it's really important to know that it can impact the way that you process information and even the way that you're able to plan ahead for just a normal week or what used to be a normal week. So that's all important to note.

Cognitive impairment can also lead to struggling with one's easy tasks, and that can be very frustrating and very demoralizing. So not only physically can it be more difficult for you to do the things that you were doing before, but now cognitively as well. And so that's like you're hit twice in a way. So that's something to keep in mind. Also, there's shared biological underlying mechanisms. So there's other things impacting the way that you might be cognitively functioning, like inflammation in the body, hormonal changes, neurotoxic effects of treatment or chemo brain as I mentioned. So these are all really important things to think about, and sometimes we always are maybe coached to notice the psychological symptoms or the behavioral symptoms, but not always the cognitive symptoms. So I just wanted to outline this.

And then in terms of evidence-based interventions, there's a few, so I want to talk about these and I think these would be really good for you to have in your pocket is tools, when you are, in a way, finding a great therapist is kind of like dating. You want to make sure that it's a good fit, and you want to make sure that they're well versed in the intervention, that could be very helpful to you. So that's why I want to talk about some of these. So there's meaning-centered therapy, and this focuses more on a sense of purpose, meaning in life value system, that kind of stuff. And it's actually based on Viktor Frankl's work. It was spearheaded by William Breitbart actually at Sloan Kettering, and I work in his department. I see him every day. So it's crazy to be working with the person that created this intervention, but it really works in that it gets down to the root of, okay, what is the meaning in my life? What are the values in my life?

And his system helps you ask certain questions that can help you out with that. So different approaches in terms of finding meaning in life could be a historical approach. So if you consider your life like a storybook, what happened in the past and how did that shape you as a person? And what does that mean for where you were, where you are and where you want to go? Also, attitudinal, so reflecting on different adversities that you're overcoming or have overcome. And what kind of attitude did you take in those situations? Did you surprise yourself? Were you able to rise up in those cases? There's a lot of work in terms of resilience through trauma, resilience through difficult medical diagnoses and chronic illness. And so it's important to tap into that. That's actually really very much a strength for you if you were able to go through that in the past.

Also, creative approach. So what do you want to make out of your life? What do you want to do? What do you want to create for people, for your family, for your friends, for even work? And that's really important. So it makes you think about like, oh, what is it that I want to leave here? What is it that I want people to know that I can do or that I do well? And then also the experiential approach, which is we're going to talk a little bit about mindfulness in a bit, and that's rooted in using your five senses. So just taking the time to go outside to feel the wind, to stand in the sand, to smell the flowers, things like that, that engage your five senses is also very important. So this has led to improved spiritual wellbeing and quality of life for people in treatment, and it's significantly reduced depression. And it's evidence-based so there's been quite a bit of research on this, which is really wonderful. So it's worked for a great majority of people.

And it's more effective in terms of as compared to supportive therapy where you're just kind of there're sharing how you feel, this is taking a little bit more of active approach, I would say. Also, this is a big one that many people know, but cognitive behavioral therapy, this is actually like a frontline treatment for many people going through cancer diagnosis. So this is a really great one and it works very well. It's also evidence-based and there's a lot of research and theory behind it, but it's more structured and it's more skills based. So if you think about the CBT triangle, I don't know how familiar you are with it, but it's this connection between our thoughts, our actions, and our emotions. So it's important to identify any kind of automatic negative thoughts or we call them ANTS. And once you identify them, you have to maybe find what is the pattern in your behavior typically, or what is the pattern in your emotions typically, when a thought like that arises and you essentially want to stop it in its track and challenge it, so it's not easy to do.

But that's why through practice and through working with a therapist and there's even workbooks out there for this, you really start to challenge those thoughts and you can sort of stop them in their tracks. They are automatic thoughts, so you can't stop the thought from happening, but you can stop the way that you react to it and what your actions and emotions are. So with this, there's been lower mood disturbance, stress and illness-related anxiety as compared to standard care. So that's why this is a very effective intervention and it's typically short term, it doesn't have to be, but you can essentially do this in six to 12 sessions, get the tools that you need and be able to try to apply it in your life and manage some of the thoughts and emotions that you're feeling and thinking. Also, I will say many therapists, if you're doing long-term therapy, use a lot of aspects of CBT.

It's peppered into, they might send you home with a bit of homework or make you think through a scenario or an automatic negative thought that you might have throughout the week. So yeah, this is a very powerful intervention. Another front line or first line intervention is mindfulness-based interventions and also stress management training. So the reason that this works is it gets you into the present moment. We like to say as therapists that anxiety lives in the future, depression lives in the past, and all you really have is the present moment. So if you think of this sort of line or a ruler, you're here, everything prior to that, if you're worried about it, is depression, and everything in the future, if you're worried about it is anxiety and you're not there yet, so really all you have is now. And so it's important to cultivate this non-judgmental present moment awareness, and you can only cultivate this through practice.

A lot of this is really working your cognitive muscle. It doesn't come easily, but that's why working with a therapist also practicing a lot of this stuff in between therapy sessions is really important because you're training a muscle, that's what you're doing, and you can use things like meditation, breathing exercises, mindfulness techniques, and all of that will reduce the rumination or this thought process that we have going to these dark places of what's going to happen, or again, why is this happening to me? Instead of that, it brings you into the current moment and lets you just deal with it right then and there and not any other point in time. Also, and I know this was mentioned, but gratitude lists are wonderful. They're actually evidence-based and proven to work very well. And again, it trains your mind just cognitively to identify positive things in your life.

And I do want to mention this is just like, I'll mention this quickly because I know we're running a little bit low on time, but in terms of stress management, you can keep a stress... Oh, wait, let me go ahead and go to the next slide here. You can keep a stress diary and I find that this works very well with patients because they identify what are the things that are causing them the most worry or the most stress throughout the day, and then what are the symptoms of it? We just talked about cognitive symptoms, their psychological, behavioral symptoms, physical symptoms like sweaty palms, things like that. So, yeah, I like to encourage people to think about that and identify a stress level for it. And then the last one that I want to talk about quickly is supportive expressive group therapy. So this is your typical support group where there's this minimize sense of isolation because we're all sharing, we're all going through what has happened and it helps build your support network.

And so I just want to conclude with, it's really important to understand your mental health and cognitive effects because it's really essential for your patient care experience and quality of survivorship. It's really important to know what are effective interventions and address this with your medical team and ask around when you're looking for a therapist, if they're well versed in these interventions to help with quality of life and outcomes. And this is just a list of resources I have here. You'll have it in the recording and I think we'll send out a list as well. So yeah, I wanted to leave enough time for questions. Thank you so much for having me, and yeah, it was really, really wonderful to be able to speak with all of you today.

Melissa Rosen:

Thank you so much. Wow. I spent your entire session between reading the slides, listening to you, and jotting down notes and questions from other people, of which we have a lot. This was not only great background information, but some really practical stuff. So thank you. Okay, so let me start with somebody asked, you mentioned to challenge our anxious thoughts, what are some examples of how one might challenge an anxious thought?

Elizabeth Malkin:

Okay, that's a great question. So if you're working with CBT, there's a lot of these over generalizations that we tend to make, and it's just automatic, right? It's like black and white thinking or over catastrophizing something. So the first part of it is awareness and identifying what it is that you're doing. So if it's a thought of like, let's say you hadn't heard from a friend or something like that, and automatic thought is, oh, my friend doesn't care. I can't trust this friendship or something like that. It's important to stop yourself in your tracks and say, "Well, am I feeling this way because it's just this isolated moment, but could my friend be maybe busy? Is there something going on in her life or his life?" Asking questions, so identifying, A, that it's happening, what are you doing? Is it black and white thinking?

Do you always think if somebody doesn't message you or call you that that means that they don't care? So first step is identifying it and then challenging it is starting to ask the questions of like, oh, let me take a step back, not think about it, not that it's irrational, but not to think about it with emotion. Just more of having these rational thoughts, logical thinking, and ask the right questions. Think like, okay, maybe there's a reason this is happening. And also you can, in this example, I guess, is eventually talk to your friend and ask and be the first one to reach out if they didn't reach out to you. That's just one example. There's actually quite a few of these that are similar to the black and white thinking and over catastrophizing. There's a lot of great workbooks out there that have a nice list of these.

Melissa Rosen:

Thank you for that. A lot of questions about the length of time that cognitive changes stay with people. Before I ask you to talk a little bit more about that, a couple of people just asked questions. So I want you to clarify, you addressed this a little bit, but could you just clarify, cognitive changes don't just happen through chemotherapy. They're not just chemo brain, right? Did you indicate that all forms of treatment as well as the anxiety of the diagnosis itself can lead to cognitive changes?

Elizabeth Malkin:

Absolutely. So the diagnosis itself, it could be the cancer in the body, it could be inflammation, it could be hormonal changes. When your body's physically affected, your body's mentally affected and your mind is mentally affected. There's a very powerful mind-body connection. So yes, it's not just chemo brain. Chemo brain is something that there's been a lot of research on, and just that makes a lot of sense given the toxicity of the chemicals. But yeah, no, it's not just chemo brain. And also, another aspect of it is the bidirectional relationship. If you are dealing with anxiety and depression, you are going to impact the way that you're cognitively functioning and vice versa. So that's another aspect too.

Melissa Rosen:

And I guess another reason to, if you notice symptoms, address them sooner rather than later.

Elizabeth Malkin:

Yeah, if you're getting treatment, obviously there's certain things that you can't control if that's affecting you cognitively, and that may get better with time. But yes, as soon as you're feeling the anxiety, the depression, the cognitive symptoms that I was talking about that go hand in hand with anxiety and depression, absolutely address it, the sooner, the better. Your medical team is really good at looking for what they're really good at looking for. And so sometimes it feels like a bit of a silo. You might have the psychology team, the medical team, there's so many different teams working, and they all can see each other's information and can help each other. But sometimes you as the patient have to facilitate that because they can't pick up on everything.

Melissa Rosen:

Okay. So if you're having symptoms, talk to your doctor, but it may not be that your doctor may refer you out. So somebody just asked, this is a perfect segue. Is there a list of types of professionals who are experienced and skilled working with these issues? Not everybody has access to the department at Sloan Kettering. So if somebody is dealing with this and they're not your major center or haven't been introduced to the right professional at the major center, who should they be asking to see?

Elizabeth Malkin:

Yeah, that's a good question, because yes, it is much easier when you work with a hospital and it's integrated and you can see the neuropsychology team, and you can't always do that. I think with the cognitive issues, it's normal to feel for some period of time, maybe at diagnosis, during treatment and into survivorship. But if you feel like there's been a big change and only you would know, you're the expert of yourself, so only you would know that you really cannot operate mentally or cognitively, I should say, at the same level as you are in how it's impacting work, how it's impacting other aspects of life, then absolutely you should seek out a neuropsychological evaluation. Because what those will do is give you recommendations and they can provide it. They provide you with a report that you could then turn around and show your work, show HR, maybe you need a shorter work week, maybe you need more breaks throughout the day.

Maybe you need certain accommodations that you can get when you have the data to back up like, "Hey, this person is really struggling with working memory or attention or executive functioning," and that's very normal, and that can happen. There's a lot of private neuropsychology clinics out there as well. You don't have to go with a big hospital, and everybody has a different pay scale for this. So it just really depends what you can afford, what is reasonable for you. But yeah, it really helps people deal with if they have oftentimes mild cognitive impairment, if you can put a diagnosis, it is a diagnosis on it, then there's certain benefits that you can get through your job. There's certain benefits you might be able to get through your community. I also work with pediatric patients, so that's like they get accommodations through their schools, colleges, et cetera. So yeah, that's ideally some kind of neuropsychological evaluation I would recommend, you can maybe provide with the neuropsychologist to what extent.

Melissa Rosen:

Okay. So another question that came in is how long after treatment can you wait to begin for it to be useful? In other words, maybe you finished treatment 2, 3, 10 years ago and you assumed that you would continue to improve, but you're still noticing you're particularly anxious or you're still noticing that you're still having executive functioning problems. Can you go a decade after treatment and still work on these things?

Elizabeth Malkin:

Absolutely, yes.

Melissa Rosen:

Great news for so many of us.

Elizabeth Malkin:

Yeah, so I work at Sloan now, but I did my internship at NYU Langone in rehabilitation. So there is something called cognitive rehabilitation, which is literally working with neuropsychologists or psychologists on these various domains. So you can work on attention, on memory, on executive functioning. A big thing that you can often change to improve memory is actually attention. So you go in, it's called cognitive remediation as the other term for it or cognitive rehabilitation. And it's evidence based, it was actually rooted in NYU, like a lot of NYU folks did a lot of research on it. So they're the leader in this space. But yeah, you'd probably need to check with insurance and things like that, but you can get just an initial sort of clinical interview and see where to go from there. They might recommend it, with an improvement in attention, you can have an improvement in memory, and executive functioning, by the way, everybody could use help with executive functioning skills.

Whether it's a deficit for you or not, it's an area that many people struggle with. And there's a lot of tools out there like executive functioning coaching and things like that, that is very helpful. And a lot of it too is also compensatory strategies. So it becomes a little bit complicated in thinking about, well, what part of this is diagnosis or treatment and what part of this is also natural aging, right? Because as we age, we're going to have some cognitive decline that's just normal part of aging. So part of it could be normal. And with that, that means writing things down more often, setting alarms and reminders on your phone, using calendars and things in an effective way. So executive functioning is a huge space that anybody could get help in.

Melissa Rosen:

Oh, great. And you were answering the questions as they were coming in, so thank you for that. We have a whole category of questions that are specific to different parts of the cancer experience. So there are questions about how to deal with pre-scan anxiety, how to deal with balancing vigilance and being anxious over any body changes, whether they're aging or an unexpected bruise that you can't remember where it came from, how to manage depression that comes from friends and family that may step back when you've been diagnosed. So a lot of those types of questions, and it's not a fair thing to ask you, but a couple of mechanisms for those very common points during the cancer experience.

Elizabeth Malkin:

Yeah, I mean, the number one thing that actually indicates how well somebody's prognosis will be is their support level in terms of just beyond just the medical stuff and the diagnosis. It's your support system. So it's really important to have a good support system. And if you're not getting that from family and friends, it doesn't mean that they don't love you or don't care about you. It's just maybe really hard for them and they're going through it too, and they don't know quite how to deal with it. And so knowing that that could be the case, then you might just have to look elsewhere. If it's not friends and family, then maybe it is a therapist, maybe it is a support group. So that is super key when it comes to treatment. So that's one of the things I'd recommend initially is sometimes it comes with time, but understand what your support landscape looks like. That's really important. And then dealing with anxiety at different levels.

The stress diary that I showed can be very wonderful in that case because I think sometimes a lot of what's going on lives up here and it doesn't get put on paper. And so when it lives up here, it becomes exponential over time. So it doesn't go anywhere if you're not sharing it with a therapist, if you're not writing it down. And sometimes when you write down on paper all of the times in the week that you were anxious or that you were stressed, and I know it seems like, "Oh my gosh, that's a big thing to do." But it can be super helpful to like, is there a pattern? Is this happening only around medical things? Is this happening around my family? Is this happening in the morning? Is this happening in the afternoon? Is this happening when I'm getting ready for bed? And then you can start to ask the questions of like, well, why is it happening in those moments?

Am I alone with my thoughts? Is there a time of day that I get triggered more because maybe a lot of my treatment or things in the past have been around that time of day or that environment? So that's where the stress diary comes in very handy. And then also identifying, well, what are the symptoms that you're feeling? Sometimes we get... It's like a visceral reaction. The only thing that just comes to mind really quickly is if you're flying in an airplane and you might get sweaty palms as soon as it starts moving and it takes off, you know that there's probably a very great chance that you're safe and everything is fine, but it's a visceral reaction. Your body just reacts, right? You get the sweaty palms. So the same thing can happen with the different parts of your journey.

Like anytime before a scan, you might notice your heart is beating quickly, your palms are getting sweaty, you are having trouble breathing. All of that, it's not just medical. It's also psychological too. And it's important to identify. And so it's like you're empowered through information. So the more that you're aware of what's going on because of what you're learning, because of your tools, the more that you can stop those thoughts in their tracks, you can turn to your support system in those moments. You can turn to your therapist in those moments.

Melissa Rosen:

Perhaps one from Sharsheret.

Elizabeth Malkin:

Exactly. Yeah.

Melissa Rosen:

You were wonderful in composing that list of resources that we're going to include in the follow-up email. I'm wondering if you can share a PDF of the stress journal that we can also share in the follow-up email, because that was such a practical solution. I saw some nodding. It resonated with me too. If you can see patterns, if you know, it makes it easier to figure out what might help. So there are so many questions coming in and we could speak for so much longer. I'm going to ask you one more question, and I'm going to just point out as a reminder now, there were questions that came in about the metastatic experience.

We've held off on asking those because there will be the breakout room with my colleague, Bonnie Beckoff, as well as Dr. Malkin, just for those who are dealing with metastatic disease or advanced cancer. So let me just end this one, which I think is a beautiful question, which was, if I notice my friend, my loved one who's going through cancer is dealing with depression and anxiety. As a loved one without medical background, what can I do to support them?

Elizabeth Malkin:

It's a really wonderful question, and it's a difficult situation to be in because we want to help, but you don't know what to say. You might not have the information or the tool. So I would just say the best thing you can do in that case is to just say, "How can I help? Can I help you find the resources? Can I help you look for through your insurance? If you're open and willing to talk to somebody, can we look for a support group for you?" So it's just how can I help? How can I help you get the resources and the support that you need?

I think that's the most powerful thing you can do for anybody in any situation if they're struggling, is just to be like, "How can I help? Let's figure this out together." Because yeah, you're right, it's difficult to have those conversations, if you're not trained and you just don't know what sometimes to say that can be triggering, right? So you want to direct them into a direction that can help them. And so yeah, just being there to help, being willing to look for the resources with them, for them, whatever they need. I think that's really important.

Melissa Rosen:

Thank you. That was a great question to end with. So as we're beginning to wrap up the main part of this evening, I want to once again, thank Kara for sharing her story and thank Dr. Malkin for sharing her expertise. It was so helpful. Somebody just... Oh, Kara just put in and very validating, so thank you for that. Thank you again to our sponsors of the program, Psychiatric Family Care LLC, Merck, Novartis, and the Cooperative Agreement 240061 of the Centers for Disease Control and Prevention. Please take a moment to fill out a brief evaluation survey that just got popped into the chat box now. You can click on it and still listen to the rest. It won't take you away from this. It'll just pop up as another screen, so you can take it now and then listen. If you are staying for the Embrace section, wait, because Bonnie will post it again, because there's a question on there about that.

We do have some exciting programs planned for the month of May, and there are two in particular I want to highlight for their anxiety-reducing impact, which is perfect as a follow-up for tonight's webinar. On May 12th, consider joining us for the moving through challenges, the importance of daily movement for those impacted by cancer. And I promise you, they'll not just be talking about how you need to run a marathon. They're going to be talking about all sorts of ways to incorporate both movement and mindfulness into your day. And the link to register just got put into the chat. And then on Wednesday, May 20th, we'll be hosting a Writing Toward Healing webinar in collaboration with Yetzirah a hearth for Jewish poetry, the link for that, and you don't need to be a writer at all to join us. The link for that will be on our website within about a week's time.

Please remember, and I say this always, I'm just doubling down on it for this webinar, please remember that Sharsheret is here for you and your loved ones. We provide emotional support, mental health counseling, and other programs designed to help you navigate through the cancer experience. All are completely free and completely confidential. Our contact information just got put into the chat box. As we come to a close, we've put the evaluation link in once more. For those of you who are staying for the Embrace Breakout, don't go anywhere. Everybody else will be getting off. And Bonnie Beckoff, my colleague, director of Clinical Services and Dr. Malkin are going to stay on with you. And so for everyone else, thank you. Have a wonderful evening, and we will get all of this information out to you within a week's time.

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

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