

In the Waiting Room: Managing Scanxiety

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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.

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Devorah Silverm...: Good evening, everyone. Welcome to our annual Sharsheret Summit, and to tonight's webinar In the Waiting Room: Managing Scanxiety. I'm Devorah Silverman, COO of Sharsheret, and I'm so excited that you're with us to explore this often overlooked topic. Thank you first to the sponsors of today's program and the annual Sharsheret Summit, Merck, AstraZeneca, Novartis, Pfizer, Lilly Daiichi-Sankyo, City of Hope, Eisai, GSK and the Cooperative Agreement 24-0061 of the Centers for Disease Control and Prevention. And thank you to Gilead for their sponsorship of this evening's Embrace Breakout Room for those facing advanced cancer. Thank you also to all of our national summit partners who are mentioned on the slides that you're viewing now.

We're proud that we'll be able to introduce you this evening to Sharsheret's newest resource called The Waiting Room and I'll give more information about that a little later on. Thank you to the generous sponsors of this new program, AstraZeneca, Merck, Natara and an anonymous donor. You were muted as you entered today's program. Please keep yourself on mute, so that we can clearly hear today's presenters. As always, this program will be recorded. No faces or names will show on the recording other than those of the presenters, but if you wish to turn your video off for privacy now, please feel free. You may also choose to rename yourself if you refer to remain anonymous and instructions for how to do that are in the chat box now.

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As you know, our focus this evening is on managing scanxiety. CAT scans, MRIs and other similar tests are used to stage cancer, check the efficacy of treatment and confirm no evidence of disease after treatment ends. For those living with stage IV cancer, these scans may happen even more frequently to monitor for possible recurrence and the same scans serve as routine screenings for those at heightened risk for a diagnosis and actually for all women. Legitimately, each scan can change our lives. Tonight, we're going to explore the symptoms of scanxiety and strategies to manage it.

We've already received many questions, which we will try to address following our speakers presentations. If you have a question to add, feel free to put it in the chat box. If you wish to submit a question anonymously, please send it only to me in the chat box, and time permitting, I will pose it for you. Before return to our medical expert. It's my pleasure to invite Meg to share a bit of her story

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with us. Meg is a Sharsheret caller who has had her own experience with scanxiety. Welcome, Meg.

Meg:

Hi. Thank you. Thank you so much. Yeah, so my name is Meg and I was diagnosed with stage II breast cancer in 2020 and Bonnie was actually one of the first people I spoke to and just a lifesaver, so thanks Bonnie. I underwent surgery, radiation, aromatherapy, AI therapies and Zometa, and actually, I just a few weeks ago finished treatment finally, but I am still, every time I go to the doctor, experiencing some form of scanxiety. And one of the things that I wanted to talk about was my very first experience with real and true scanxiety and it was after I got diagnosed.

I was diagnosed actually by my OB-GYN after I had had my baby and she was also a breast cancer survivor. And the first time I went back to see her, it was the middle of the pandemic. I had just had my surgery done and I had done ultrasounds after because there were some concerns as to whether or not they got everything. And I was going to talk to her about what was happening, what to expect next. And this is during that time period where we all had to wait out in our cars and we couldn't go into the waiting room. And so I was waiting in my car and the women at this clinic have known me for years. They were there for me through both of the births of my children and I'd been there weekly for a while.

And as I'm sitting in the parking lot, I get a call from the receptionist and she's like, "It's time to come in." And I had a full-fledged panic attack sitting in the middle of the parking lot because I couldn't function. I couldn't go in. I couldn't go anywhere. And the women there have known me, like I said for a long time, and Trish, the receptionist, on the phone, she says, "I have two options. I can either get you to come in, maybe I'll get the doctor out there, that'd be great or we could just do your yearly out in the parking lot. Which do you want to do?" And it was really jarring in trying to get me out of it and it worked and then my doctor came out and talked me through it and talked me through how to do some of the techniques of grounding and how to schedule things to help reduce scanxiety.

And one of the things she talked to me about was when you have to do these appointments and things, when you schedule them, sometimes it's better actually to schedule them first thing in the morning on a Friday because you're not going to get the results that day. You're not going to get them at 5:00 on a Friday, so you're not going to ruin your weekend. And you can start the week off when you do get the results being able to make plans and be actionable, which oftentimes anxiety, what you needed to have is action. Doing something decreases that anxiety quite a bit.

Also, she recommended little treats and who doesn't love little treat? I still, like I said, experience a lot of scanxiety every time I go in for my mammograms. It's really weird to think that this is where I am forever, where every year I'm going

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to go get my mammogram and who knows? Hopefully, nothing comes up, but I'm not in control of that, but I'm really looking forward to hearing more tonight and I really appreciate the opportunity to speak and tell my story about my little panic attack in a parking lot and how my doctor came out and rescued me. So thank you so much. I really appreciate you all.

Devorah Silverm...:

Wow. Thank you, Meg. That was really very relatable and I know I speak for everyone in saying that we appreciate your candor and your generosity in sharing your story. It's really important that we all know that we're not alone in feeling the things that we feel and you've helped us tremendously. So I'm excited now to welcome Dr. Kristina Espinosa, an accredited clinical psychologist at the Miami Cancer Institute. Dr. Espinosa specializes in providing evidence-based integrative and individually tailored psychotherapy that focuses on the biological, social and psychological factors that influence health and wellness.

She uses a combination of methods and tools for mindfulness-based psychotherapy, cognitive behavioral therapy, attachment theory and trauma-focused therapies to help patients find meaning through life's most difficult transitions and hardships, including cancer, chronic illness, grief, pregnancy and infertility, trauma and relationship challenges. Prior to joining the Miami Cancer Institute in 2021, Dr. Espinosa was a psychologist at the Children's National Hospital and is a member of the American Psychosocial Oncology Society. Dr. Espinosa views therapy as a safe place to explore, observe, find meaning in and heal from the pain that accompanies the human experience. She's honored to walk alongside her patients in their cancer journeys. Dr. Espinosa, thank you and welcome.

Kristina Espino...:

Thank you. I appreciate it. I'm super excited to be here. Thank you, Meg, for sharing your story. You highlighted a very personable but also very relatable experience. I'm going to start sharing my screen, so we can jump right in onto today's presentation. You let me know if you can see it, how I see it. Let's see here. You cannot. All right, hold on, one second. There it goes. All right, and it should be moving. Little squiggle lens. All right. So my name is Dr. Espinosa. Thank you for that beautiful introduction. I am a clinical oncology psychologist at Miami Cancer Institute. I'm going to be presenting In The Waiting Room: Managing Scanxiety and I'll start out with some ...

I have nothing to disclose. This is an educational presentation. I have no relevant financial relationships and so this is meant to really provide that psychoeducation and also provide a collaborative discussion as it relates to something quite common. Today, I'm going to be talking about a variety of different things. I'm going to define what is scan anxiety. I'm going to distinguish it from general cancer-related anxiety. As you could see, Meg referred to, "I had a moment of panic," and so I'm going to really quickly go over panic disorder versus phobia versus scan anxiety, which is very different, very unique.

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I'm going to talk about the psychological and physiological challenges that patients face during the scan process. We're going to explore some stressors that are specifically tied to the pre-scan and post-scan periods. I'm going to discuss some strategies, right? Some tangible strategies that you can use pre, during and post that are going to be extremely helpful and they're evidence-based. And then I'm going to provide some tools not only for patients but for clinicians as well and caregivers to also be able to implement. Okay, so I'm going to try to be as informative but also entertaining because I know how late it is too for a lot of individuals, so we'll make this quite informative and fun.

So when we're thinking about cancer-related anxiety, anxiety's normal, okay? That flight or fight experience, we want that. And when we say we, as humans, anxiety is the number one emotion that keeps you alive. Anxiety says, "Hey, there's a threat to my life or to my safety," and like Meg alluded to, we want to control that threat so that we survive. We thrive beyond the threat. So anxiety is common. It's common in a cancer diagnosis and within treatment context. Where we start to see an issue is when it's chronic, okay? So patients often experience fear, uncertainty and stress and they're related to a variety of different stages in the journey, from diagnosis to treatment to outcomes. But scan anxiety refers to the unique form of anxiety, okay?

It's transient like Meg also illuminated for us. It happens just right before, during, waiting for the results and it's specifically surrounding scans, okay? Very different than an anxiety disorder. An anxiety disorder would be that as if Meg worried all the time, more often than not, and was not unable to really find relaxation from her worries, right? It impacts sleep, nutrition, exercise and her social relationships. That's when we start to think about a disorder, but here, we see it as transient and specifically around scans. So what is scan anxiety? It affects about 70% of patients.

So it is quite common and it's seven out of 10 really experience that level of anxiety as well. And you can experience it at any time point, okay? Before, during or after. And then there is an emotional component to it and there may be panic as well. And that panic is the feeling of dread, the feeling of you can't control this moment and then it will subside shortly after once the scan is done or once you get results, okay? So very common. And when we're seeing anxiety disorder, we're now looking at about 23%, okay? So you could see that jump from 70% all the way to 23%.

Less people have anxiety disorders within the cancer oncology population, although it exists. So we do know that and that's what we treat. When we say we, I'm talking about us, me, psychologists and psychiatrists within Miami Cancer Institute. So we know anxiety can arise at various stages. We can see an anxiety disorder look like a panic disorder, which means that there are multiple panic attacks or we can also see phobias, okay? So I do often hear individuals when I'm working with them that they might say, "Oh, I have claustrophobia and sometimes with scans," that happens too, but oftentimes, scan anxiety is

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really transient, right? It comes, it goes, it ebbs and flows where an anxiety disorder does not or it means pretty constant, okay?

So the psychological components, individuals might really fear, fear disease progression and recurrence. So these are the most common of thoughts that I hear. "I'm just waiting for the next shoe to drop, right? So if this scan came out, positive or unremarkable results, you know what? The next one, the next one might be the one where the shoe drops." That's very common. Another anxiety related to scan anxiety is hypervigilance to bodily symptoms. So this might be, "I have been having this headache," or, "I have a pain on the side of my neck. I wonder if that's cancer." That's also very common, right? "I feel a new pain. It must be cancer."

The next is rumination and catastrophic thinking. We call this zero to 100, right? You're thinking about the worst possible scenario, right? "I just know they're going to find something." It's also what we also call fortunetelling. So fortunetelling, catastrophic thinking and rumination are all part of what we call cognitive distortions within the psychology world. I'll talk to you a little bit about that when we talk about cognitive behavioral therapy, which is a treatment we offer. And then there's a lack of control and uncertainty. So Meg had stated, "Well, anxiety is this desire to gain control," and she's right. Anxiety wants to gain control because it wants to stop the threat.

So oftentimes, anxiety manifests with scans because the scan is part threat and so too are the results, all right? A threat to life and wellbeing and safety. So now we're seeing your flight or flight is getting activated when it thinks about the potential of what a scan can bring into your life. So how does it affect you physiologically? Well, there could be sleep disturbances right before the scan and even after. You could have these panic symptoms or somatic complaints. A lot of GI issues are also very, very reminiscent of flight or fight. You can have emotional dysregulation, so a heightened sense of irritability, a low frustration tolerance. People might say around you, "You get edgy around time of scan or you're thinking too much," right?

And so there's just this criticism that you're just not tolerating or you're not relaxing or thinking positive, but because it's actually quite scary, right? Getting closer to the scan is very scary and is a real threat for you and so it makes sense. It does. And also, there are social and occupational impacts, right? You may not be able to meet some deadlines for work. You may not want to hang out with some friends right before. You might isolate. These are all behaviors that are very related to when you feel a threat is coming, okay? You are self-preserving is what's happening.

So I'd like us to think about the timeline of scan anxiety. We have pre-scan and that is that anticipatory worry, "The bad things are going to occur. I just know it." Procedural anxiety, "I remember the techs. I wonder if that tech is going to be there." So that your mind starts to fill in the blanks and tries to control the

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situation at hand, so you might have that anxiety before and then during, right? So some people will tell me, "I have claustrophobia," or, "I have a fear that I have to do radiation all over again or I have to do chemo all over again and there really is this discomfort during the scan." And those are those intrusive thoughts that are happening during and then post.

Post scan is, "Okay, now, I got to wait for the results I got to know." And so I like how that nurse was so helpful in saying, "You know what? Let's do it on Friday, so you can have the weekend to relax and you'll find out on Monday," but how technology works nowadays, sometimes you will get a ping in your portal that you did get a new result. So I'll let you know how can we best approach that. It's going to be really important. The peak of scan anxiety happens in the waiting period and really because the hardest part is that you don't have control. I often ask my patients and I would like you to think about this as well, reflect on your life too, what in your life have you had 100% control over? I'd like you to just think about that.

In your life, what have you had 100% control over? And oftentimes, I'll hear people say, "You know what? I don't think anything, right? I actually don't think anything." And I'd like us to ground ourselves in realizing there's a lot that we do not have control over and there's a lot of things that we are naturally allowing to happen and then we're able to recalibrate as needed. So the hardest part of the waiting period, it's not so much that you can't control it, but that there's this part of you that feels that the outcome will be negative. So that's the part where we have to just edit just a little bit. So there's two ways we can see this. We can cope in a healthy adaptive way where we can try to remain neutral as possible.

We can use affirmations, "I'm safe in this moment. I'll be able to handle what lies ahead," and lean into support and redirect attention or we can go into the maladaptive, unhealthy. We can ruminate. We can keep thinking. We can repeat conversation themes. That means we might actually talk to someone and repeat ourselves, "I think this is when the shoe's going to drop. I just think about it," and then you just ruminate or constantly checking your portal or the new thing, ChatGPT. It's a double-edged sword. I love ChatGPT, but at the same time, googling and really being your own scientist sometimes can lead down a rabbit hole that could create more anxiety.

So ambiguous or delayed communication causes distress and that's why you and your medical team, you have to have this really powerful and trustworthy relationship. Because the more that they are ambiguous or they're not on time with your appointments or scan dates, that just puts more worry on your plate. So this period, the waiting period tends to be the most stressful for individuals. And so who's most at risk? Individuals who have had ... If it's their first time, you're very nervous because it's the unknown. But then another risk factor is if you've had repeat scans, and likely for a lot of different treatments, you will need repeat scans in three months, in six months, in a year.

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And so sometimes we call this like a re-traumatization of, "Well, I hope this isn't like the last time," or, "I hope it doesn't get worse." So we've got first timers and then we have repeaters and these are the two that are most vulnerable to experiencing the anxiety. History of trauma or anxiety disorders is another risk factor. If you have been in positions within your life that you have been faced right in front with threat to life or safety, this mimics that. Scans and regaining results mimics some of that fear that you have had when you have had to face traumatic events, unfortunately.

There's a really great book. I highly recommend it for some. If you yourself are aware that you've had a trauma history, there's a book called *The Body Keeps the Score*. It's phenomenal. It's a beautifully written book. It's got science, but it's also got personal histories and it really talks about how the body just doesn't forget. It doesn't forget, it remembers, but it doesn't know how to disseminate between a true threat and something that appears familiar, okay? So the body doesn't forget, but it does keep score in that, if this feels like a threat and if it feels traumatic, the body responds in the similar way.

A lack of support. So if you don't have a trusted system, you are more at risk for experiencing anxiety that is debilitating, or if you have a personal or family history of cancer, this likely is going to heighten that experience for you. I'm going to go over some tips and techniques, okay? I'll go one by one and I'll try to make it as tangible as possible, but we're going to target three different areas. We're going to target cognitive, behavioral and mindfulness and relaxation. And Meg talked about a little bit of grounding techniques, which is some of that behavioral and mindfulness and also talked about getting a sweet treat, which is also behavioral.

We'll talk about it, but I got to hit you with the cognitive first. And the reason is because some people will say, "I just feel anxious immediately," and I say, "Well, wait a minute," because our emotions actually follow our appraisals. Appraisals just means how we think about things, okay? So I often give this example, when people wake up in the morning, you have the one person that wakes up and goes, "Ah, it's another day. It's another day that I got to do the same thing over again," and then the other person, another person wakes up and goes, "It's a brand new day. It's a brand new day, right?" So you have two different people, it's a brand new day for both, but they both perceived it differently, so they're both going to feel differently about it.

So now what I would like us to think about is cognitive reframing when it comes to scans. So the first one is you got to identify the trigger. What is it that immediately sparks this pit in your stomach, this sense of nervousness, this sense of dread? You got to figure out what's the first thing. The second is to recognize common anxious thoughts like, "The next shoe's going to drop. It's just going to get worse. I'm going to run out of luck," something like that. We've got to realize that our thoughts sometimes play tricks on us and make us more anxious.

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Three, you want to choose to challenge it. I always welcome a challenge and I want you to challenge thoughts that make you more nervous, because likely, likely, they may be rigid in nature. So we want to add flexibility, and that way, you're going to be able to overcome the anxiety. Four is to develop a support system. We'll look at that. And five is to plan scheduled worry time. It means that, in your day, you're going to go, "Okay, this is the time I'm going to worry." You can ruminate as much as you want, get as nervous as much as you want. You will not die from a panic attack. I'm going to let you know that. Panic attacks do not cause heart attacks or strokes or anything like that. You will not die from a panic attack, but you're going to need to wind down from a panic attack. I'll teach you that too.

This is what it looks like. This is what a cognitive plan looks like. It looks like this. All right, I'm going to identify the trigger, "And sometimes, I get super anxious when I have to book the scan, when it's the day of, when I'm in the waiting room during it and the results." So I have to figure out which one is the one that triggers me the most. Then I'm going to think about what are the thoughts I'm having, "What if they find something wrong? I won't be able to handle bad news," things like this. These are some of the thoughts that we think about when we think about cognitive distortions or anxious thoughts.

And then I'd like you to think about how to choose to challenge it. So the way we challenge it is by saying, "I've had scans before and I've managed them and I'm going to be okay. If I know the results now, it doesn't mean that it's going to be bad, it may be good, right?" So that's duality of it and you can handle whatever happens, "Do you have access to resources? Do you have a support team? Do you have a team you can trust?" okay? So really I want you to challenge the distortions that say, "I can't handle this," and that's how you do that. Now four could be best friend, family member, therapist support group. The more, the better, but also quality, okay? So you want to make sure that you are able to rely on these individuals and they don't make you more anxious.

And planning a time to worry. This might meet 10 minutes after work. You might put a timer and say, "Okay, that's it. I'm going to worry for 10 minutes," and you can just ruminate. But once that timer's done, it's time to redirect attention. It's time to be action-oriented and that's going to be really important, not to ruminate the whole entire time. Now, mindfulness strategies are a little bit more behavioral in that you can apply these right before the scan, during the scan and even after, okay? So it's focusing on being in the present moment and "being grounded", which means that, if you've ever seen children play, they're playing. If you say, "Okay, it's time for recess, let's go outside," they're outside, meaning they smell the grass if there is grass. They see other children, they're really immersed.

They're not thinking two, three steps ahead in the future. Mind you, their frontal lobe isn't fully developed, so they really can't if they wanted to, but for the most part, they're very present-focused. It's what I invite you to do. I invite you to be very present-focused without thinking two, three steps ahead. So you

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might practice grounding techniques and that might be using your five senses, five things that you can see, four things you can touch, three things you can smell, two things you can hear, one thing you can taste when you feel disorganized, dysregulated.

So for example, you might be in the waiting room and some people will tell me, "I'm in the waiting room, and sometimes, I don't even know I'm in the waiting room. I just feel like I'm in a dream or I feel like I'm not really there." That tells me that you were in a flight or fight, that it might be you might have some derealization, that you're separating in the sense that it's just too overwhelming, so your body's trying to cope by trying to numb out a little bit. So that's when I invite you to be like, "All right, let me bring myself right back in." You might use aromatherapy, you could use if you're able to and it's cleared by your doctor, you might use some lavender, some eucalyptus bring you back into the moment.

You might silently repeat something like, "I'm safe, I'm present. I can handle this moment," and you might focus on the meaning of why you're there and focus more on your breath, okay? You might also be able to hold something tangible that feels of comfort. Some people have something of faith and a value and you might put it in your pocket and you might be able to say a mantra, "I'm safe in this moment. I'm protected in this moment." That'll really help. I like to go over some behavioral exercises. Structure distraction routines and self-care planning work.

So let's say the cognitive right now is a little bit just too challenging or cumbersome and it might be and you might need a therapist to help you get that started. Behavioral techniques is where it's at if you're going to try any of these techniques. All of you are quite familiar with distraction. We are often distracted by the tablets and our phones and everything, the pings and social media, but I mean a structured distraction that actually is going to help you and not just distract you or what the Gen Zers call brain rot, okay? I'd like you to do something enjoyable but also that is actually pretty healthy for you and then self-care planning, okay? We'll talk about what that looks like.

So let's look at structured distraction. This is really going and doing something that you truly enjoy and slowing things down, okay? You might like reading if you have a Kindle or you actually have a tangible book so you can turn the pages. I want you to slow things down, whether that's reading, whether that's knitting, whether that's drawing. The thing about our phones and doom scrolling, that means you're just going through Facebook, you're just going through Instagram is that you're not able to take in ... You won't be able to take in a lot of information, and two, you won't be able to slow your thoughts down. If we slow thoughts down, we also can regulate our breath.

If you've ever noticed you're on your phone, pay attention to your breath. Are you holding it? Sometimes, people will hold it and some people go, "Ahh," and

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that in and of itself shows dysregulation in breathing. So I'd like you to slow things down, take it easy and I want you to notice how you breathe when you're drawing, when you're doing a crossword puzzle. You may want to do puzzles within the waiting period. I love ... It's Wordle. I love Wordle. It's free and it's by The New York Times and you're able to do those things that when you're in the waiting room, keep your mind busy, engaged, and then after the scan, I love how Meg was like, "Well, plan some treats." I agree.

I think you need to plan an enjoyable outing. You need to think, "You know what? I'm going to get with my friends after this scan and we're going to play whatever together, chess or Monopoly or something like that or we're going to go out to eat." I want you to think about living as well as doing what you need to do in terms of your treatment protocol. Oftentimes, individuals will think, "It's just the cancer journey." It's not uncommon for individuals to get consumed in that way, but you also have to live your life alongside this level of suffering, okay?

Now, self-care planning, really it's three-pronged. We have physical self-care. That is your exercise, that is your walking, gentle stretching. Emotional self-care, so this is connecting with someone that you trust and you love and you feel seen and heard and practicing relaxation strategies. And then there's practical, which is preparing your belongings before you go to the appointments. Maybe having a support person take you if you'd like that. Some people like to go alone or also planning transportation, so that you don't feel like you're going to run late to the appointment, you're going to be on time. This is all preparing you for that moment and also after, okay? So self-care planning, I like to think of it as self-preservation. It's allowing yourself and giving yourself the best shot each time.

We're almost getting through. These are additional coping strategies. Normalization and validation of your feelings is paramount, okay? It's okay to feel scared. It's okay to feel nervous. So if anybody tells you, "You just got to be positive. That's all you got to do," I'm going to say no. It is okay for you in that moment to feel like things are not going to be as positive. That's okay. I just don't want you to stay there for too long. I want you to acknowledge your feelings and then I'd like you to push yourself a little bit ahead and get more neutral. I want you to establish a routine, not to get stuck in the rumination, but realize that your life is also happening alongside these scans and alongside treatment.

You want to limit unhelpful checking. So if you're the type of individual to constantly check your portal, I urge you to set a time and a date. When you do. Individuals, I often recommend that if you do get the results, don't look at them. Wait until you meet with your medical team to look at them and to go through them because the worst thing is for you to interpret something. I'm going to tell you, I'm going to be very candid with you, I'm seven months pregnant, but initially, my reading comp isn't great. I interpreted all the results incorrectly and I panicked. And so the best thing to do is just wait for the doctor and then have

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a discussion with them and then they tell me the results and then I'll google it thereafter, but I learned my lesson.

Point is you want to wait. You want to stay socially connected to those you love and then stay physically active. A lot of research is pointing out to exercise, is a phenomenal and sometimes outperforms an SSRI for certain individuals. I urge you, if you can take a walk, if you can exercise, it's going to be wonderful. And then you want to prepare for the results, okay? You want to prepare for the results and that might be you might know where you feel safest in your home. That may be where you want to take the call or you may want to a trusted person to come with you to the visit when the results are revealed, okay? So this is careful planning that you're doing for yourself throughout.

A lot of question marks, I don't know, but that's cool. Maybe there's a lot of questions. All right, so the role of a clinical psychologist. So this is what we do. We provide psychoeducation and we provide psychoeducation on just better understanding anxiety and how it's manifesting for you. I don't tend to overpathologize. So a lot of my patients, I'm like, "You know what? This is quite normal and for you in particular and let's just normalize some of your emotional responses. Then we'll go ahead and we'll make some meaning. We'll make some meaning of what's going on and realize how we can better emotionally regulate that works for you."

Now there is brief psychotherapy. I really, really like cognitive behavioral therapy. It's evidenced-based, solutions-focused, time-limited. It's really nice. I also like acceptance and commitment. That's a little bit longer, a little bit more fluid and it can be very helpful with feeling as if you don't have control. Okay, so there's CBT, ACT. So when should you see a psychologist? Honestly, when you think the symptoms of anxiety are impeding your ability to go to these scans, okay? When it interferes with daily function, when you're turning to maybe substance or maybe you're turning to maladaptive coping. My biggest one too is avoidance and that's a big one or if there's any depression that you're feeling, this depressed mood and any signs of complex trauma or PTSD, okay?

So if you are feeling like, "Okay, a lot of things are getting in the way of me going to these scans and it's just getting in the way of my life," this is the best time to seek support. Some digital tools. There's some apps I highly recommend. My favorite is Insight Timer. It is free. There is an option to have a subscription. Don't pay it. I like the free. It's great. It's great for meditation and mindfulness. Insight Timer, what you can do is you can choose the type of meditations. I tend to like guided imagery mostly, but there's also body scan meditation, which is really nice and then you can choose the author, the narrator and what feels right for you. So Calm is also very well-known and so is Headspace. I don't know if it's Netflix has a Headspace channel or something like that.

Patient forums and support communities. I like that. That's wonderful as well as oncology-specific psychoeducational platforms like this, like American Cancer

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Society, ASCO, CancerCare. So in essence, scanxiety or scan anxiety is normal. It is a very distinct psychological experience. 70% of individuals experience it so you're not alone, but it's important you understand timing. When does it happen the most? Triggers and tools is key. I heard Meg say, "This is something I'm going to have to deal with for the rest of my life, this kind of anxiety because I'm going to have these scans," and I want to offer hope, because as I hear that, I want to offer hope and plant a seed that it doesn't have to be that way.

You can feel a little bit of those butterflies and jitteriness, but it doesn't have to be every single time. You'll like a multidisciplinary approach, so that might be you have a therapist or you have a support person or you have groups like this where it's such a large community that you can be able to share your experiences and tips and tricks. There are ways to get through this anxiety, meaning you can overcome it and I think that's so exciting. You can. And when we're thinking about anxiety disorders, it's going to take a lot more work, but it's possible, but with scanxiety, it is totally, totally curable. Alrighty, those are my references and I'm here for questions. Thank you.

Devorah Silverm...: Wow, that was just a lot of really useful and helpful information, Dr. Espinosa. Thank you so much.

Kristina Espino...: Of course.

Devorah Silverm...: We have a bunch of questions that have come in and I want to also give a chance for people to post questions in the chat box, either privately to me or to the whole group and we'll share those as well. Let's start with this one. Somebody asks, "How can we learn to live a 'normal life' in between scans?"

Kristina Espino...: So beautiful. Okay, the first part of normal ... The only thing that's normal in this world is a button on the washing machine, all right? So we'll take that. So a lot of us are very unique in our own individual ways. I'd ask you, what's your baseline? What is your baseline? And if your baseline is someone who is just more engaged with others and everything like that, you may want to think of scans as one part of your life, but still making sure in your routine throughout the week, you're sticking to something you are used to doing. There's no ifs and buts about it. You commit.

So it's like you're not letting things kind of fall at the wayside. You're committing them through the routine and also through those affirmations, meaning, "There's a beginning, a middle and an end to the scan and my life will continue on beyond that too." So it's keeping that affirmation in mind. Grounding and keeping your routine.

Devorah Silverm...: Okay. Somebody else shares, "Part of what makes me feel anxious is that the scans don't show the whole picture of what's going on. A PET scan, prior to my ovarian cancer surgery, didn't show half of what they found when they went in.

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How do you deal with the anxiety that you never really know what your actual cancer status is?"

Kristina Espino...: Wow, what a powerful question and very common. I don't really like to say that our medical team is not capturing it all, but the truth is our medical team, unfortunately, sometimes does not capture it all, in the same way that sometimes they'll say, "Well, maybe it'll come back. Maybe it won't," when we think about fear of cancer recurrence. Fear of cancer recurrence is normal, affects 80% of individuals, and yet, we're not able to predict whether or not cancer will ever come back. So there is this level of uncertainty and unknown that unfortunately can be inevitable, but what I see as a line of hope is that, as long as you are very plugged into your medical team and when you doubt your medical team, you seek a second opinion, I think that is what's going to be as proactive as you can because there are aspects that we cannot control. Yeah.

Devorah Silverm...: So I think you touched pieces of this next question, but I'll ask it anyway. "What specific techniques or strategies would you offer to someone whose scanxiety is preventing them from scheduling screenings or from actually going to keep the screening appointments?"

Kristina Espino...: Okay, so great question. Great. That's moving beyond scan anxiety, right? Scan anxiety is that you have anxiety, you go, right? Now when there's avoidance, we're now looking at a little bit more into anxiety disorder or pathology. So what I would say is, if you're noticing you are avoiding, I think, if you're able to have access to seeking professional help, this is of a psychologist, social worker, licensed mental health counselor, this is when the time is and to help you through that.

Devorah Silverm...: Okay. So a few questions that came in the chat. "What do you think of EMDR or Flash Technique?" This person's understanding is that some therapists use this with patients to help cope with scanxiety as opposed to CBT and ACT.

Kristina Espino...: Yeah, yeah, beautiful. I don't use it. It is efficacious, meaning it does work, it's evidence-based, I just don't use it, but it's great if you would like that more mind-body connection as opposed to ... Behavioral therapy is really targeting those thoughts, head on. EMDR, it is a nice transition and into understanding how your body becomes dysregulated when you are anxious. So it is that paced breathing. It's realizing when you get overstimulated. So it's beautiful. It's as efficacious, although CBT tends to be very mainstream in academia and medical settings. Yeah.

Devorah Silverm...: Can you remind us please about the book that you mentioned and the author, what the title and the author's names are?

Kristina Espino...: Of course, this is *The Body Keeps the Score*. I want to say van der ... I have no idea. My recall stinks, but when you look at *The Body Keeps the Score*, it will come up. It's super popular, but I highly ... There's a disclaimer. The disclaimer is

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that, if you've experienced and you know this about yourself, a history of trauma, this is going to be that book. If it's not, it's going to be quite jarring when you're reading. It might not relate to you. So it has to be, if you have that insight to know you have a trauma background history, *The Body Keeps the Score* is a beautiful book.

Devorah Silverm...: Right, okay. Somebody shares that her significant other told her that she was catastrophizing and she's struggling with responding constructively to her support person when the support person is perhaps trying to help deal with anxiety, but it doesn't feel like it's supportive help.

Kristina Espino...: Okay. Probably because we're using terminology that maybe professionals should use, right? The thing about in social media, I hear a lot of other terms, people are using like gaslighting or invalidating or, "You're being narcissist," throwing these words that are very charged, negatively charged. So I would say this. I would say, if someone is saying, "Well, you're going to zero to a hundred and you're catastrophizing," and using those terminology really to set that boundary that that name in and of itself or that label doesn't sit right for you. So set that boundary first.

The second is, if it is not as helpful, the communication, you may want to communicate what might be more helpful for you. Now, if this is a caregiver, in particular, here at MCI, caregivers also can be seen by our social work team as well as myself and so then we can have sessions with them too. So you might need external support if it becomes prevalent and consistent, but setting boundaries.

Devorah Silverm...: Great, okay. Another person shared that she feels particularly anxious when doctors explain that they're going to be sharing results by the phone instead of at an in-person appointment, because then every minute, there's worry about the phone ringing, but with an appointment, there's a set time. And so this person shares that she can focus her anxiety around the appointment. Any advice for that kind of experience?

Kristina Espino...: First, I want to give this person a lot of credit for setting that boundary as well because that's incredible. I think, if you're able to express that to your team and them to honor it, that's beautiful because you'd like to be able to set limitations. In terms of the phone ringing, everything like that, if they can only do it through phone, you may want to do a different ringer for that particular number. If it's a hotline number for the hospital or something like that, a different or have it on a vibration instead of ... So you're not queued every time you get a phone call, but I love it in person. I agree, to be able to stick to that.

Devorah Silverm...: And it sounds like you're suggesting that a piece of self-advocacy is being able to say to your medical team, "Any way we could have this meeting in person instead of by phone?"

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- Kristina Espino...: Absolutely. Yeah.
- Devorah Silverm...: Okay. So another person shares that she's six years out from her diagnosis of a genetic breast cancer, found a lump, had a mastectomy and now goes in for an ultrasound in the axilla every six months. The ultrasound is painful and it's a difficult process. The scan was clear and now they're saying they want this person to come back every six months and she feels traumatized by that experience and is wondering if you have any specific suggestions for her.
- Kristina Espino...: Absolutely. I think when we're thinking about ... I mean, congratulations that the scan is clear. I want to just acknowledge that, but also the behavioral techniques of grounding mindful ... There's the body scan meditation. You could do it on Insight Timer. Just google it. It's an application and then there's body scan. I highly recommend you try that. And that way, you can learn tools to regulate, and so when you become back into a memory or trapped like schema, cognitive schema, you can bring yourself back to the present moment, "I'm safe. I'm okay. This isn't the same as last time," and then regulate the body through breathing and imagery. So I would say behavioral techniques and body scan in particular. Yeah.
- Devorah Silverm...: Okay. A couple more questions. "How would you suggest that people find mental health professionals who specialize in this type of treatment?"
- Kristina Espino...: This type of treatments? If it's CBT or a CT, a lot of clinical psychologists, generalists are trained.
- Devorah Silverm...: I think it's more around the anxiety issues than the specific interventions.
- Kristina Espino...: You're right. Most clinical psychologists are able to address anxiety. Now when we're talking about oncology, that's a little harder. There aren't as many of us in the community. We are embedded within the hospital setting. So that is the downside of that, but in terms of anxiety, there's a lot of clinical psychologists that you can ... There's a portal. It's psychologytoday.com. It's a good search engine. What you can do is you'll pull up providers and then you'll just put your insurance. You'll put your location. You can do virtual, in-person and then you put anxiety, okay?
- Because they can treat the scan anxiety because it's not a true diagnosis, but the clinicians will be trained to be able to help you. So you can put that. So that's a great tool. It'd also go through your insurance provider and see the psychologists.
- Devorah Silverm...: Okay. Somebody shares that, when she knows that a test is coming up, she can't plan anything for the days or the weeks after the test because she's worried that the results will be bad. And it affects her at work, it affects in her personal life and is wondering if you have any suggestions.

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Kristina Espino...: Yeah. So that will be cognitive reframing in that moment, okay? So what I heard was, "I can't do anything because I just think they're going to be bad." The thing is that the results may be not favorable and it may be favorable. So I'd like you to keep it more neutral. And at the same time, whatever you do from now until you get the results will not change the results, so keep that in mind. And so that's why it's important to keep going because the time will come when it will be revealed. And then at that point, that's when you make the next plan, the next decision. Yeah, so that's reframing, cognitive reframing.

Devorah Silverm...: And I think the last question that we have is, what to do about, what this person calls, scan exhaustion?" So it's not necessarily anxiety. It's about wondering how this person can keep up with the regimen of scans and screenings for 30 years.

Kristina Espino...: Wow. Yeah. So that is just that fatigue, that absolute fatigue. What I would say is to then reframe and be able to ... I like guided imagery. I do like it. And that's going to be able to put you in a different headspace every time. There are things you also do in your life repeatedly that cause exhaustion as well. And so how can you change the parameters of it? How in the moment can you allow your mind to go somewhere else, somewhere more pleasant and do that diaphragmatic or deep breathing grounding techniques, so that the whole entire moment doesn't consume you?

I always say this to patients, "Your mind can be a prison or a garden," okay? And so another really great book, I don't like the title, but it's Man's Search for Meaning. I wish it was Human Search for Meaning. It was written a long time ago by Victor Frankl. And so he really talks about suffering and in repeated suffering and where to find meaning in it and wherever there's a will, there is a how. You can bear almost any how if there's a will. So I like that book, Man's Search for Meaning and also reframing and grounding and guided imagery.

Devorah Silverm...: Thank you. I'm just looking to see. Somebody else has sent something in. "Do you have any thoughts to share about how someone might be able to avoid passing on anxiety and worry to people in their family, in their close orbit?"

Kristina Espino...: Well, that's hard. So how to avoid to pass it on? It depends. If we're talking about children, all right, so that needs better regulation on our part because we know that anxiety is both genetic, but also behavioral, right? So what they see, what they do, how they ... But if we're talking about other members in our family, that's something we cannot control. We can only control ourselves and how we regulate, but we really can't control others. I wish I had a better answer, but no, I don't think we can.

Devorah Silverm...: Thank you again, Dr. Espinosa. Really, really helpful information. So at the start of this evening, I said that I would share some information about something new that we've been working on to support you and to support your loved ones. And we're happy to debut our new support resource that we call The Waiting Room. Sharsheret social workers, Bonnie is one of our Sharsheret social workers

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with us this evening, our social workers are poised and ready to help you and your loved ones navigate what many consider to be the worst part of any challenge, the unknown.

We have support, resources and years of experience to help you during the moments when your future feels out of your control. If you're waiting for results, call us, so we can provide you with support and wait with you. In addition, we've added new Waiting Room webpage resources to our website. You'll find additional resources to help you through these unique times. The link to the new page is in the chat box now. I encourage you to check it out and to share it with anyone who you think could benefit from it, patients and caregivers alike. I want to thank Meg for her generosity in sharing her personal story and Dr. Espinosa for sharing her expertise, her experience and clearly her passion.

A reminder for our Embrace community, we invite those who are facing metastatic breast or advanced ovarian cancer to stay on at the end of tonight's webinar for an intimate breakout session with Dr. Espinosa and Bonnie Beckoff, our director of Support Services. Please take a moment now to complete a brief evaluation survey. The link is posted in the chat box now. You can click on the link and still listen to the last few moments of the program. As we conclude, I want to share a little more about our annual Sharsheret Summit for Breast Cancer and Ovarian Cancer Awareness Months. We're already halfway through our amazing schedule of national webinars and upcoming programs include webinars that are focused on nutrition and cancer, another on managing cancer treatment side effects and many more.

The Sharsheret Summit has its own website. Let's post that link now, please, in the chat box. Here, you can check out all of the programs, national and local, register for webinars and learn more about Sharsheret partners and sponsors. You can register for each of these webinars through the Sharsheret Summit website or through the regular Sharsheret website and we'll put that link in the chat box as well. And of course, a reminder that our wonderful dedicated team of social workers and genetic counselors are here to help you address your concern. You won't be the first to share them. Please don't hesitate to reach out. Our contact information is in the chat box now.

Thank you all for joining us tonight and we look forward to seeing you at future summit programs. Again, we'll put that survey link in. Thank you for your time and for your feedback. And we invite our Embrace callers to stay on for that intimate conversation with Dr. Espinosa and Bonnie. Enjoy the rest of your evening.