Facing Scanxiety

With Dr. Lidia Schapira, Stanford Medical Center

National Webinar Transcript

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Presented by:

SHARSHERET
The Jewish Breast & Ovarian Cancer Community

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Melissa:

Okay, welcome. Welcome, and thank you for joining us at tonight's webinar during this difficult time. Let me begin by saying that Sharsheret stands with Israel. We mourn with the families and friends of those killed, pray for those injured and captured and hope for lasting peace. As our hearts are focused on Israel, Sharsheret continues to provide vital cancer support and education to the thousands who depend on us. This webinar, tonight's webinar Facing Scanxiety is the opening webinar for our 2023 Sharsheret Summit, Pink Teal and You, which brings together thousands of people virtually and in person all across the country from October 13th through October 31st.

We hope that you'll join our national virtual symposiums on the latest hot topics in breast cancer and ovarian cancer, attend or host in-person education or awareness raising programs with community partners across the country, learn more about the latest screening guidelines and access the most up-to-date data and materials in our digital resource packet. Our upcoming webinars are being added to the chat now. However you choose to participate, our Sharsheret Summit is the source for the latest information on breast cancer and ovarian cancer. I want to take a moment to thank Gilead and our Sharsheret Summit sponsors, Daiichi-Sankyo, GlaxoSmithKline, Merck, AstraZeneca, Pfizer, Seagen, Lilly, Natera, Eisai, GE Healthcare and Northwell Health Cancer Institute. We now have a special message from our Sharsheret Summit lead sponsor, Daiichi-Sankyo.

Gissoo:

Hello, my name is Gissoo Decotus. I'm the global head of Advocacy and Strategic Relations at Daiichi-Sankyo. We live our corporate mission of passion for innovation and compassion for patients every day as we work to make a meaningful difference, not only from a therapeutic perspective, but by also helping ensure people receive the information and support that they need throughout their cancer journey. We value our partnership because your organization, like ours, seeks to make sure that people living with cancer are connected with the trusted sources of information and a community of support, and that all patient voices are heard. You all inspire my team and me every day as we work to bring innovative new medicines to the people who need them through our ongoing research efforts.

Melissa:

Thank you. In addition to our very generous partners, we have what we call Summit Program Partners and the following organizations have partnered with us to help get the word out about this important education: 18Doors, AEPhi, Vassar Center for BRCA, Cancer Support Communities and Gilda's Club, the Cooperative Agreement DP-19-1906 from the Centers for Disease Control and Prevention, Clean Speech New York City, the JCC Association of North America, the Jewish Orthodox Feminist Alliance, Jewish Orthodox Women's Medical Association, J Screen, the Network for Jewish Human Service Agencies, 1 in 40, One Table, Ritual Well, Sviva, Women of Reform Judaism and Woman to Woman.

Before we get started, I want to remind you that tonight we have a bonus session for our Embrace community. We invite those facing metastatic breast cancer or advanced ovarian cancer to stay on at the end of the webinar for an intimate conversation with Dr. Schapira and Bonnie Beckoff, director of Sharsheret Support Services. Today's webinar is being recorded and will be posted on Sharsheret's website along with a transcript for your reference. Participants names and faces will not be included in the recording. Still, if you'd like to remain private, you have the option to turn off your video and rename yourself or you can call in to the webinar. Instructions on how to do that are in the chat box below for both options.

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You may have noticed that you were muted upon entering the Zoom. Please stay muted during the call. If you have any questions, please feel free to send them through the chat and we will do our best to answer as many questions as possible during the scheduled Q&A at the end of today's presentation. We recommend you keep your screen on speaker view; This will enable you to see the doctor's presentation. And as we move into the webinar itself, I want to remind you that Sharsheret is a national not-for-profit cancer support and education organization that does not provide any medical advice or perform medical procedures.

The information provided by Sharsheret and by tonight's presenter is not a substitute for medical advice or treatment for a specific medical condition. You should not use this information to diagnose a health problem, and of course if you have any questions, you'll be advised to speak with your medical advisor. Please always seek the advice of your physician or qualified healthcare provider with any questions you might have. Now, before we begin the program, I want to introduce Fran, a Sharsheret caller and a peer supporter who will share her experience with scanxiety.

Fran:

Hi, my name is Fran Guzzi. I'm a retired teacher from New Jersey. I was diagnosed with triple negative breast cancer in August of 2020. It was difficult because it was during COVID, but I did my best to put my one foot in front of the other and just get through as I had a lumpectomy, chemotherapy and then radiation. All that ended in the spring of 2021. Since then, I've been able to find joy again. I live life now with a level of enthusiasm and gratitude that I did not have before. I try to enjoy each moment, each day, but unfortunately twice a year something gets in the way and all that goes out the window. I know now that it's called scanxiety and that scanxiety is something that's normal, most people have it, but it's really uncomfortable. And when I begin to feel that anxiety, that scanxiety, I know that I have tools in my tool belt that can help me through, and so I'd like to share them with you.

The first is that I have a journal. When I'm starting to feel uncomfortable, I take out my journal and every night before I go to sleep, I try to write down three things that brought me joy that day. They can be very small things because I don't allow myself to repeat them day after day. Something like the foam on my coffee or the red flower I saw when I was walking or a joke that my son shared with me that night when we spoke on the phone. Knowing that you need to embrace the positive even when your life is hard, even when you're feeling anxious I think is really, really important. I also write down my fears, because in writing down my fears before I go to bed, it almost puts it on the paper and gets it out of my head and I feel lighter and it's easier to sleep.

Talking about sleep, I go to my next tool, and that's mindfulness. I have an app on my phone called Insight Timer. There's many of them, but I like Insight Timer and I use it to do a short meditation every night before I go to sleep, and often I'm asleep before the meditation even ends. I even meditate during the day, practicing my breathing and mantra, and sometimes in the morning to set my intention for a positive day. They even have meditations for scans.

Then the next tool that I would say is to stay busy. The day before my third year scan, which came on September the 21st, my friends got in touch with me and asked me if I wanted to go to theater. That was September 20th, and I said yes. I didn't even ask what the play was because it didn't matter. I wanted to be with them, and while I was with them, I shared my fears, I got hugs, and it really, really helped. Finally, I would say to you, reach out to Sharsheret. Having Sharsheret behind you is such an important thing. My social worker, Aimee, has been such an angel in my life. Whenever I'm feeling fearful, she just makes me feel better. She gives me perspective, she understands, and I always feel better after I speak with her.

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I also would suggest that you think about having peer support with another person from Sharsheret. I work with and have become friends with someone who's in Chicago who's also a triple negative cancer survivor, and she and I talk all the time. We've become good friends. Once scanxiety comes up, she's like the best person to talk to because she really gets it. My other friends try, but she understands it in a way that I think other people don't. Then also, if you are a person of faith, reach out. Reach out in your faith. When I was in temple on Rosh Hashanah, I spoke to God and I asked him to help me. When indeed I was waiting for my scan results and I'm nervous, I'm talking to God. It's comforting. It's helping. My friends and family prayed for me and I was grateful.

Well, on September the 21st after my three-year scans, I drove home with great gratitude because I got really good news. I'm okay. My husband looked over at me and said, "Fran, next scan, are you going to go through everything you went through this time?" And I shrugged and I said, "I don't know, but probably. But if I do, I have tools in my tool belt that can help me through." And that it doesn't take the pain away, but it does help you manage them. Thank you so much for listening to me and I hope that these tools will be helpful to you also.

Melissa:

That was wonderful. That was absolutely wonderful. Thank you to Fran for her willingness to share her tools with us. I know she was on the right track because I saw this evening's presenter nodding the whole time. Now this evening, we are so honored to be joined by Dr. Lydia Schapira. Dr. Schapira is a professor of medicine at Stanford and the Director of the Cancer Survivorship Program at Stanford Cancer Institute and Comprehensive Cancer Center. She's a board certified medical oncologist with 30 years of clinical experience and trained in hematology and oncology at the Brigham and Women's Hospital in Boston, and then completed a research fellowship at the Division on Aging at Harvard Medical School.

Dr. Schapira's clinical practice is dedicated to breast cancer. At Stanford she directs a multidisciplinary research and clinical team focused on optimizing health outcomes for cancer survivors through research, clinical care, education and advocacy. She's been invited to lecture at professional meetings and multinational forums throughout the world and has championed research and clinical initiatives to integrate mental health care in oncology and to improve health outcomes for people living with and beyond cancer. Dr. Schapira, welcome and thank you for being here. The screen is yours.

Dr. Schapira:

Thank you so much, Melissa, for your very, very kind words. I think Fran gave us a masterclass in handling scanxiety. I'd like to contribute a little bit based on my years of sitting with and being with and accompanying patients who have scanxiety. I was there when this term was coined and I celebrate the fact that it is because it refers to such a particular form of anxiety that should, it deserves to, be separated from what we normally think of as anxiety. I'd like to just share with you some thoughts, perhaps respond to some of the questions that have already been submitted and welcome new ones. And even talk a little bit about how we can take some of these common issues and transform them into research questions to find answers that may be able to benefit more people who are coming down the pike. Certainly to be able to help teach the clinicians to better support patients, to listen to them when they're saying that they're anxious, or even to elicit those concerns in a more systematic way. I'm going to share my screen. I don't think I'm able to.

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Sharsheret:

You should be able to under “more”.

Dr. Schapira:

Under share screen I am not able to share. Basic [inaudible 00:15:51] see if I can do it now. I think it worked.

Sharsheret:

Yes.

Dr. Schapira:

Can you see this?

Melissa:

Yes.

Sharsheret:

Yes.

Dr. Schapira:

Here's a bit of a graphic representation of what comes to my mind when I think about anxiety. It's in a way you're spiraling a little bit, you feel that you're less in control, and I think that for the next 20 minutes or 30 minutes, however long this takes, maybe we'll all feel a little bit uncomfortable just thinking about what it's like to feel really that you are out of control. Let's talk a little bit about anxiety. This term scanxiety was coined I think now in the early teens around 2011, and it refers to that increased level of nervousness and anxiety a person feels around medical tests. Now, they could be scans, they could be medical appointments, they could be blood tests. I think that the scan sort of represents the testing or the evaluation piece. And so let's think about it a little bit.

This could be something that you feel in the weeks or days before a scan, a test and an appointment. These scans or tests or appointments for somebody who's already been diagnosed with cancer are usually scheduled for surveillance to make sure that the cancer remains in remission, or for people living with advanced cancer, they're often scheduled to see if the treatment is working. There may be different things going through people's minds. In some cases they're used, again, to monitor the progress of a therapy, in which case it's an important discussion that will follow the scans, especially if the scans show that the disease is not properly controlled, that there are new sites of disease. As Fran was telling us, in many cases, these scans are done to confirm that there is no evidence of cancer. In other words, in a way, to assess, validate, confirm that the treatment for cancer has been effective and that person is in remission or cured, depending on the situation.

Now, some people also refer to scanxiety to denote feeling nervous during a scan, and that's important as well. During those minutes or hours when you are physically subject to a test, whether you're inside a donut and unable to move, I assume everybody on this call has had some form of a test in their life, and so we all know what that feels like, that vulnerability, that nervousness. If somebody's ordered a test, it usually means that there's possibly a diagnosis that needs to be confirmed. We've probably all gotten used to also doing scans for screening when we don't have disease and we enter into those perhaps

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with less anxiety than when we are going to have a test to follow up on a condition that's already been diagnosed and to see if a treatment has worked.

Dr. Schapira:

Many people talk about scanxiety as persisting. So it's not just the days or weeks before, it's not even those moments when you are vulnerable and getting the test, but it's all of those days, I hope not weeks, but in some cases it may be even weeks until you get the results. In other words, until there's a resolution, until you know what those results are. We can talk a little bit about how people receive these results and whether or not it makes a difference if the results are conveyed shortly after a test by somebody you know and trust and are in relationship with or whether you are sort of left wondering. In this day and age, as we'll talk about in a few minutes also, many of us feel very vulnerable because the results of testing are released directly to the person or patient or survivor, whatever word is comfortable for you.

And physicians such as myself can't control when that information is released so we know that our patients are receiving test results before we've had a chance to look at it, which is not the best way to do this. We don't feel comfortable with it, but we have no say, so that requires a little conversation as well. One of the questions that I think we all have and many of you have asked is, how can I prepare mentally for scans? And I think Fran gave us so many tools, and so let me reflect a little bit on this. First of all, I would say we can prepare mentally and physically. I think that it's time for us to think about also what kinds of physical activities may promote a state of calm and acceptance. I think that's where we're going with this.

We know, for instance, that we're going to be facing the testing and the scans. That those will be, for the most part, separate from the moment where we receive those test results. They may be separated by hours or days, perhaps weeks. The issue is, how do we get there? And we know from what patients have told us, we've even looked at this through research, that we have even physical symptoms of anxiety and stress in the days preceding these tests. I would say that one of the first things that come to my mind when I think about this, and jot down what comes to your mind perhaps to make this conversation more useful to you, is to be aware of what you feel and to begin to be aware.

Dr. Schapira:

Fran talked about journaling. Well, I would invite you all to even journal what a typical scanxiety cycle feels like for you. When does it start? Does it start 7 days, 10 days? Does it start three hours? Does it start the day prior? And then once you start to think about or become more aware of when you're starting to feel things, then you can begin to even think about what kind of a plan you need to get through that period. Again, this can be, and usually typically is, more than one day. It's a little bit of time. Then the question is, how does it affect you? Are you feeling physically nervous or is it interrupting your sleep? Are you distracted at work? Is it interfering with the ability to experience joy in life or joy in the things that normally bring you joy?

I think all of these things are important because they help us understand how important this is for you. In some cases that may also help the person that you then turn to give you advice that works for you. Is it something you can solve? Is it something that requires perhaps a social worker, a buddy, a group to help you with? But these are the kinds of things that I would say are important. To prepare first is to be aware of when it starts, how it's manifest, how it interferes with your life. And then we can get to, slowly over this conversation, the kinds of things that work for you perhaps in other settings in your life to soothe you, to calm you. Since it's something that we've decided that in general that we need to

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accept in order to stay healthy, we need to get these tests done. The question is, how can we prepare and regain some control?

Anxiety can also come from reading results on an online portal before the doctor or nurse practitioner calls you to review those with you. This is the comment that we got from one of you who wrote it in. I don't know how you all have resolved this in your own lives, but these little prompts that come on your phone or your computer, you have a new test result, what are you going to do? Are you going to ignore it? Are you going to open it? If you open it, are you going to open it while you're at work maybe and take five minutes and then risk having that information really distract you or take you to possibly a dark place? I think this is really key here too, as I was thinking about this and thinking about preparing, it's preparing for the test, for the physical act of the test, but it's also preparing for this period of anticipating results and knowing what to do.

Dr. Schapira:

I have read and heard some incredibly creative approaches to this, and maybe some of you have read the same testimonials that I have, but there are people who basically make a plan to open this, the test result, with somebody in a safe space or to do it in the waiting room right before they're about to meet the oncologist. They basically have maybe an hour to look at it, but they're going right into a place where these test results can then be discussed. The information gleaned from these tests is then used to make a plan of action. But I think this is really important because it can really, I think, sort of ignite that flame for people who are already very anxious about all this.

Another comment that has been shared with us that I wanted to address is the anxiety that perhaps also lives in the same family. The anxiety that's triggered by having no standard of care for routine testing or for rare cancers. That, I would say, is a little different from scanxiety, but that also takes us, if you just react to these words, that means that the person who is experiencing this feels vulnerable and feels alone, feels isolated because they're in a situation perhaps where it's not clear what needs to be done next. This is something that perhaps some of you who are living with advanced cancer feel when you are getting multiple treatments, when you've perhaps participated in some clinical trials and you are reminded that you're in a situation where either there is no one single path forward. And so that can also, again, contribute to having people feel that they're anxious or out of control.

A lot of scanxiety really has to do with that, with feeling that you really can't control what's happening. And so the scan, in a way, becomes a symbol of all of the things that test result or that procedure represents, which is that there is an illness, that you are vulnerable, that there's uncertainty, that you may have done absolutely everything possible and you may love your clinical team and feel very comfortable with the care you're receiving, but still there's that feeling of uncertainty and vulnerability until somebody absolutely assures you that you are cured. That moment often doesn't come soon enough or doesn't come at all for some people.

Dr. Schapira:

Another comment that was shared that I think we need to work through is the sentiment, I have trouble after the scan waiting. Too many traumatic openings of emails. How do I make this easier? And this speaks to preparing for that waiting period from the test to the resolution. I think that some of the comments that Fran made today help us here as well. Again, if we are thinking about this, the one thing that immediately comes to my mind as a clinician is, is it possible for you to set the date of when you're going to receive the results at the same time as you schedule your test? Then at least you know how long it is that you're going to have to wait, and perhaps you can control some of that meeting for getting your result. If you think that you are traumatized by opening emails, then is it possible for you not to

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open them? Is it possible for you to have scheduled a meeting with your clinical team, whether it's a nurse practitioner, the oncologist, within 48 hours or 72 hours of having the test?

Having some control, even expressing this to your clinical care team may lead you to be able to partner with somebody on the team in order to have a plan. Having a plan, a plan that you've invested in, a plan that meets your needs, I think can help abrogate or mitigate some of those feelings of uncontrolled anxiety. As with any other situation where you just simply have to wait, then I think again, all of those wonderful tips that Fran gave us come into play. Staying busy, calming the mind, calming the body. If you like to exercise and you're able, exercise until you're really physically tired. Talk to somebody, don't wait alone, ask for help. Think about calming, soothing, mindfulness practices, gratitude practices, anything that puts you in a place of relative calm.

Again, the way I would respond to this question is, you need a strategy. You need a strategy with your team to figure out when those results will be conveyed. Then you need a strategy and a plan for keeping yourself as calm as you possibly can, understanding that it is going to be a difficult time and feeling supported, feeling that you have people there with you and having things to do so you don't have a whole lot of time where you're vulnerable to having those feelings.

What works for you in similar situations is the first question that I would ask and what I ask when I'm sitting with patients who talk about this. Waiting for test results or feeling that the illness and the diagnosis and treatment occupy this space for you is really very important. But if we just for a moment put that to the side, I would ask all of you, and I would guess that each one of you has faced other difficult situations in your life, that you've had moments of crisis or that you've been there with people that you love and mean a lot to you. What has worked for you? I would start with that. Who are you? What works for you? What gives you comfort? What soothes you? And the answers may be very different, but again, some of the answers may be that there may be some physical activities that work for you. It could be singing, it could be cooking, it could be watching comedies. Perhaps you are somebody who is very spiritual or religious, then finding that that practice helps you sort of regain your calm. Maybe you absolutely are not spiritual or religious, but you're a runner or you're a dancer. Maybe doing a lot of that.

Look, I had a patient out whom I will never forget. I've had several patients who taught me, for instance, one was a dancer and one was a biker. I will never forget them. They're in front of me right now, I see their faces, who would get their chemotherapy and then go dancing or bike until they were so sweaty that they had to really... They were exhausted. But the point is that if you do have something that you can do to become more tired, to distract your mind, to really engage in something, whether it's something spiritual or an activity or physical activity. And then of course asking for help. Being supported is always helpful. I would say, and then think about your strengths. Think about something that you have done in your life where there was a real crisis and what helped you through and think about what you learned from that and see if you can bring it forward.

Dr. Schapira:

One of you wrote, and I'd like to respond to this, "I was diagnosed with metastatic pancreatic cancer in my early thirties, and I am in remission. I've been managing my anxiety more effectively than I once did, and I'll be curious to know what it is that helped you. But scan day seems to be increasingly rough on my partner who comes with me. How can we manage a caregiver's scanxiety?" And I'm bringing this up right now because I think this is also really important and I don't need to tell anybody on this call that cancer happens to families, that cancer affects care partners, caregivers. Again, there are different terminologies and some people prefer one term or another. I'm sort of agnostic to the language.

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But the important concept here is that there's somebody else in your immediate circle who's a big support for you, whom you love and cherish, who's also suffering from this.

I'd like to address this for a couple of reasons. One is that as a clinician, we don't reach out to care partners as much as we should, and we know it. We would like to. There are all sorts of reasons perhaps why we don't. We don't feel that perhaps we want to intrude. If somebody comes across as being supportive and strong and you ask a general question, "How are you doing?: And they say, "I'm fine," sort of leave it there without probing. But I know that some caregivers and care partners who feel very much alone, they're perhaps not so great at asking for help, so let's just look at this for a moment and dissect it.

I would say that in my view, the care partner or caregiver's scanxiety is just as important as the patients in terms of the fact that we need to respond to it, we need to support. And the same advice that I would give somebody who's experiencing scanxiety is the same advice I would give the care partner, find somebody else to talk to and ask for help. Perhaps each person in a partnership here, if these are spouses or domestic partners or a couple, or it could be that even the situation could be mother, daughter. If there are two people who are very tightly involved and they're both having issues or one of them is having issues, it's important to ask for help for somebody else. Each person deserves their own person. Perhaps the care partner in this case could ask for help or reach out for help, or as a couple, you could ask if there is a mental health worker on the team or a social worker that you are already working with to also extend their help.

I think that these are the kinds of things that I want to make clear that we recognize that the emotional health of caregivers and care partners is very important, that we know that clinicians don't often reach out as much as we should, and that it's important to pay attention to the mental health. This is very important and there's some research that has been done in the last 10 years looking at mental health of cancer caregivers. As you may intuit, and as you may guess from the way that I'm delivering these comments, we know that the caregivers, care partners mental health actually also impacts on the health outcomes of the patient.

Clinicians know that if one person in the team is suffering from anxiety, depression, distress, the other person will be affected as well. It's very important I think, to think about the person who supports you and to help them also to ask for help and reach out if they need it. There are many interventions, again, as a clinician scientist or as a physician that have been tested in clinical trials for which there is evidence that help relieve or help tolerate the anxiety. And the anxiety that is felt before, during, and after scans, after all, is anxiety. I think some of the ways that we can think about what we can do and how much of each one you may want to do or how you may work it into your coping schedule, I think Fran gave us a master lesson in saying that actually having a strategy and figuring out how much of each she needs and when, it's like dosing your interventions, actually helps her.

That would be my approach to this, to try to figure out what the data is like what is the period when you're feeling this anxiety, what works for you? How much of each of the things that work for you do you need and how often? So that's what we normally do with medication. What can help? Well, if you're in a machine and you feel claustrophobic or you feel anxious or you feel nervous, some form of relaxation exercise, which we think of as a breathing exercise, can be enormously helpful. Listening to music if you are able to during a test. If you know that every time you have a scan, a mammogram, a blood test that you freak out or feel uncomfortable, you have pain, whatever, anticipate that and try to figure out what you can do. Tell the technician that if you're anxious. Try to see if you can soothe yourself a little bit. There may be a medication if you need it that can help you, even something very simple to help diminish the pain if the scan itself is uncomfortable.

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Relaxation, some form of breathing, and then in certain cases, even medication. I certainly have patients for whom certain tests are incredibly painful and we need to take care of that as well. Mindfulness and meditation are wonderful tools. There's a lot of evidence of course, that they work, but they need to work. They work if you are ready, if you've prepared, if you know how to do it. It's difficult to improvise. Just like I wouldn't tell somebody to go ski on a steep slope if they've never put on the skis before, it's hard to tell somebody to go meditate if they don't have a practice. I think learning some of these techniques can be incredibly helpful. But again, it takes a willingness, it takes commitment to learning. There are many apps, there are many places where people can learn. I'm certainly not an expert, but I think that most of you probably know or have somebody who can recommend a way to access both mindfulness practices and meditation.

Dr. Schapira:

I think music is a phenomenal tonic for the soul. I think art is great and helps us overcome traumas. But listening to music can be incredibly helpful while you're getting treatment. These days with AirPods and headphones, we can isolate ourselves. If being in a waiting room while you're waiting for your name to be called causes anxiety, close your eyes and listen to your music, whatever is calming for you. Visualization exercises I think can also help if you can think and bring yourself to a place. Imagine yourself in a place where there's calm and there's beauty and there's no excitement, that can also be really helpful.

Bringing somebody with you to a test. Most people have the comfort or the ability to call somebody who's probably happy to comfort you. I think if you don't ask people to help you, they don't know how to do it, or you may actually be giving them a gift if you say, "I have a scan in six months and I would like you to accompany me. Can we schedule it at such a time that we could be together?" And then plan something, maybe having lunch afterwards or doing something with somebody that is dear to you and maybe you don't see them that often, and that person may feel that you've just given them a huge lift by actually asking them to be with you and to support you.

The practice of yoga has been studied extensively in the world of supportive care and breast cancer. For those of you who practice, I probably don't need to convince you, but for those of you who've never heard of it, let me tell you that it's an effective way of reducing physical symptoms. Again, there's a component of mind body movement and breathing that may be very helpful as well. Self-hypnosis is not talked about a lot, but really helps. There's an app that I certainly know, at least there's one app that was developed here by one of my colleagues, David Spiegel. I've heard him present it at meetings. Self-hypnosis is really an amazing tool for getting through difficult moments. If you haven't tried it, I'm sure that you can probably also find a way of doing this.

Then there are other interventions also like Tai Chi and Qi Gong that have been studied. These are all evidence-based and can help people in different situations. But again, you need to know how to do these things and you need to know when to do them, and you need to know for how long to do them, for them to really work.

In thinking about this in closing, I would like to also bring up the fact that sometimes you need professional help. That while scanxiety, we want to make it normal and validated, if really the symptoms start early, they persist a long time and they're really very difficult for you, then I think it's really important to ask for professional help. You can ask the people that are already a part of your care team or for wonderful support organizations, but there are ways of getting help.

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Dr. Schapira:

Then I think that one of the things that I as a clinician deal with a lot is the sort of very fine line that separates monitoring your body from being hypervigilant and panicking when you feel something. Maybe we can talk a little bit more about that in the Q&A, but that's hard. We've studied, my team and I have studied it in young kids who survived childhood cancer. We recently did a study, we're looking at results in young survivors of breast and ovarian cancer. We really want to try to understand how people react to physical symptoms because as an oncologist, when a patient asks me, "What do I look out for? What are the symptoms?" I try to have a conversation, but then I already know what that may lead to. There's a very fine line sometimes between knowing that if you feel an ache in your body, it could be a sign that you have metastases in your bone. Then what are you going to do when your mind has already taken you there? So that may be something we may want to talk about a little bit more.

Then I just have two slides that I wanted to end with because some of the questions that have come in really have to do less with anxiety and more with communication challenges. I think these things are different. For instance, if there's anxiety about test results, but the issue is that you don't know how to interpret them or you've had different opinions and you say, "Who do I believe? How do I know who to trust? How can I possibly decide whose recommendation if I have two different opinions?" And this is something that appears to be happening from speaking to others and support groups. When I see questions like this, I think that it's important to think through what we're saying here. The issue here is that there are situations where legitimately, there may be two experts that have different opinions, and then it may be difficult to sort out and know what to do. I would be very happy to talk more about this if it's helpful to any of you.

But in general, my high level advice is make sure the person that you're taking your questions to is really an expert in the subject matter. Then try to figure out if there's something you don't understand or is there really an issue of trust? Because if you don't understand something, then asking for an explanation is important. Sometimes different experts have different communication styles and they may not be saying something that's totally different. There may be situations, again, where there's no standard of care and so two different experts may give you different recommendations for treatment, and both can be legitimate. When I see questions like this, I have a very hard time just giving one solid answer. But I would say try to break it down into as many components as you can based on how you chose the person that you asked, why you went to consult with somebody, and if you really need help, see if there is somebody else in your care team, maybe a primary care physician, a gynecologist, somebody else who can help you understand and unpack what seems to be contradictory advice.

The final one, and I'm always sad when I see these questions or these comments, is that when you feel that you've been dismissed or when the explanations aren't good. I think these are two different things when feeling dismissed is bad, I don't think that that makes for a good therapeutic relationship. If you have cancer, you want to have a good therapeutic relationship with a clinician. You may not love your radiation surgical or medical oncologist, but you need to respect them and like them a little bit so that you don't really dread seeing them. If you do, maybe that's a sign that there's some sort of an incompatibility. I am sorry for those who feel dismissed. I hope that it's not just that somebody is in a hurry. Sometimes these things happen.

I think that if the issue is that the results aren't explained clearly, then that's something that I think could be worked on. Again, my quick advice there is to make sure that you communicate and you have a few questions, maybe three or four that you ask quickly and you say, "I need to understand this better," or "I don't understand this. Can we schedule another time to go over this?" But you should have a clear understanding of the results.

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Now the results may not be exactly what you hope for, but you at least need to be able to understand it so that you know if you need another opinion, if you need to prepare yourself for a change of treatment, or sometimes even the results may be better than you anticipated and you're still left with some questions. With that, I'm going to end and stop sharing and take your questions.

Melissa:

Thank you so much, Dr. Schapira, that was so helpful for all of us who wait for results. You were very thorough, but I have a few questions. And if you have a question for Dr. Schapira, please, this is the time to put it into the chat box. I'm noticing that our questions, some of them are about scanxiety specifically, but some are just about cancer and anxiety in general. If you're comfortable, we may go to both of those places. I'm going to ask if you wouldn't mind talking a little bit about what's appropriate to expect? In other words, maybe we can reduce scanxiety if we're provided with or if we're not provided with, we ask beforehand. In other words, my thoughts were, what exactly is going to happen during the test? How long should I have to wait for results? What are they looking for very specifically? But I'm sure you have other things that someone should know beforehand.

Dr. Schapira:

Look, I totally agree with you. I'm the kind of person, if I have to drive someplace, I would want my GPS to tell me everything and say, "Oh, that was well done. Yes, there's going to be two more lights before you actually have to even think about changing lanes, and you just passed this red building and that's fine. That means you're going in the right direction." I think that if we use that kind of analogy, Melissa, I think that what I would want and what I hope I've tried to do for my patients is explain, as you say, exactly why a test is being ordered, what it can and cannot show us, what one test will tell us, how I will use that information to give a recommendation, whether or not that test is absolutely necessary, whether or not there are other tests that can help us understanding and why.

And this goes all the way from new molecular tests to pick off cancer cells in the body that some people want. Then we have to have a conversation about perhaps why that is or isn't indicated to why we still order mammograms. Even, for instance, when somebody keeps telling me, "But the mammogram didn't detect my cancer, why do I need to do it?" And these are legitimate questions and I think they require communication and discussion. Clarity is important. Asking the questions and asking them in a tone that basically says, look, I want to understand. Then from the clinician's point of view, I think this also sets us up for having a better conversation about the test results. If I say to somebody, "I'm going to order the test. If the number of the cancer antigen is the same as it was before, I'll consider that a successive treatment."

I don't need it to be better because first what I want to see, for instance, is that the number stabilizes. Anything that's within 10% of what the last one was, I will consider a good result. I try even to if you-

Speaker 7:

That's fantastic.

Dr. Schapira:

... to teach my patient how I'm going to interpret it in. Then we look at it in a side by side way. If they want to look at the portal and see the number, they'll already know, they'll have been coached by me about what to look for. Over time they become better experts even in handling the data, and less dependent on me, which is fine for both of us.

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Speaker 7:

That's great.

Melissa:

Can you talk about some of the symptoms of scanxiety? Because I'm guessing that some people have it and don't even realize that's what it is. I know there are emotional symptoms and there are physical symptoms. Could you go over that for a minute or two?

Dr. Schapira:

Sure. Scanxiety, if we just think about anxiety, you feel it in your body, perhaps. Some people may or may not be aware of it, but you may feel it in your body. Your pulse may be a little faster, your heartbeat may be a little faster, you may get a little caught up in your breathing, you may be breathing a little faster or you may be nervous, you may be sweating. You may have people who are wired to feel everything in their digestive symptoms may have a little nausea or a little cramps or not want to eat or want to eat or not know when to stop eating, or some people may sleep too much or too little. It could be all of those physical sensations like when you have a final exam or when you need to do something that is really stressing you. Symptoms of stress can also represent certain symptoms of anxiety because again, we're thinking that as somebody who has had cancer, people feel stressed or distress, and then taken to the next level, that could become anxiety. Anxiety is when these kinds of normal stress symptoms get more intense and they don't go away, and then they reach a threshold where they become real problems. That's what I wanted to put in front of people to say a little bit of this may be fine, but if it really is almost disabling, then people need help.

Melissa:

That's great. You know what? We have a few more questions, but I need to be mindful of time. I'm noticing that you were very, very comprehensive, which was amazing, and you weren't able to watch the chat because you were speaking, but so many people putting in suggestions of their own and supporting one another, so amazing. As we begin to wrap up, I want to thank Dr. Schapira for her insights, her passion on this topic and remind all our Embrace callers that we will continue with a private session after these closing remarks finish. Please take a moment to fill out a brief evaluation survey that is linked in the chat box right now. Anyone who completes the evaluation will be in the running for a chance to win an Amazon gift card. But more importantly, the evaluations really do inform future programs, so please take a second. Again, that's going to be in the chat box. There it is. I see.

I also want to thank once again our sponsors and our program partners for tonight's program and for the Sharsheret Summit overall. Of course, the 2023 Sharsheret Summit continues throughout the month. Join us next Monday at the same time as we discuss pre-implantation genetic testing, on Thursday, October 26th for Sharsheret in the Kitchen with cookbook author and Sharsheret board member Kim Kushner, and on Monday the 30th, as we close this year's summit with a webinar on AI, on artificial intelligence and how that's going to impact screening and treatment in the future. The link to learn more was just put into the chat box right now. I see it there.

Melissa:

Of course, please never forget 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 your cancer experience.

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All are completely free, completely confidential, and our contact information is in the chat box right now. Somebody just put in that they just remembered and they're so bummed they missed it. But don't worry, if you registered, you will get a copy of both a transcript and the recording. Anyway. Our social workers are here, as well as our genetic counselor, available to each of you. You are our priority. We're here to help you with whatever is on your mind at the time. Again, world events are very stressful, particularly when you're dealing with a cancer diagnosis, and we want to keep our stresses controlled as possible.

One more time, please put the link to the evaluation in the chat box, and we now invite members of our Embrace community, those facing metastatic breast or advanced ovarian cancer to stay on for our breakout session, sponsored by Gilead with Dr. Schapira and Bonnie Beckoff, Sharsheret's Director of Support Services. For everyone else, thank you for joining us and goodnight.

Bonnie:

Thank you so much, Melissa

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