



SHARSHERET[®]

BEYOND CANCER:
MANAGING MEDICAL ANXIETY

Presented with generous support from:

The Cooperative Agreement DP19-1906 from the Centers for Disease Control and Prevention



MARCH 26, 2024

Melissa Rosen

Welcome and thank you for joining us tonight for something very important. In fact, tonight's webinar acknowledges a unique part of the cancer experience, the transition from active treatment to survivorship.

But before we begin, I do have a few housekeeping items to share. So first, I want to thank Daiichi Sankyo and Merck, as well as the Cooperative Agreement, DP19-1906 of the Centers for Disease Control and Prevention. Their generosity allows us to continue to offer important support in educational webinars such as tonight's program.

A reminder that tonight's webinar is being recorded and will be posted on Sharsheret website along with a transcript. Participants' faces and names will not be in the recording.

We did receive some great questions and a lot of them through the registration process, but I am sure questions will arise during the webinar itself. So please use the chat box to ask them and we will have our speakers address them during the Q&A session at the end of tonight's webinar.

As a reminder, Sharsheret has been providing telehealth services to the breast and ovarian cancer communities for over 20 years because cancer is so much more than simply a physical experience. And as we move into the webinar itself, I also want to remind you that Sharsheret is a national non-profit support and education organization and does not provide any medical advice. The information provided by Sharsheret and by tonight's speakers is not a substitute for medical advice or treatment for a specific medical condition. And you should not use the information provided tonight to diagnose or treat a health problem. As always, seek the advice of your physician or a qualified health provider with any questions you may have.

We have a lot to explore tonight, so let's get started. I think one of the unique parts of the cancer experience is that when it's over, it's not done. I know that sounds odd, but stay with me. While we are dealing with the diagnosis or in a form of active treatment, whether it be surgery, chemotherapy, radiation or something else, we know that we are doing all we can to ensure we return to health to increase the likelihood we stay healthy, and there is a lot of comfort in that. And we have our healthcare team of doctors, nurses, and other providers easily accessible to answer questions and reassure us when we have concerns.

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

And as we transition away from that active treatment or are beyond that active treatment, not only are the members of our healthcare team a bit less accessible. After all, we're not seeing them regularly, but we have so much time because treatment can be time-consuming. And with so much time available to us many use that time to worry.

Again, it can be a challenging transition. We worry about our health. We have questions that need answers both about our continued physical health and the emotions surrounding our concerns. My own personal one then and now is how am I supposed to tell the difference between recurrence and normal aging? And those are some of the issues that we're going to address tonight.

We have two amazing healthcare professionals with us tonight. But before we have them join us, I want to introduce somebody very special. I want to introduce Audrey Kerr. Audrey is a Sharsheret caller who has her own story to tell about this, and she is joining us right now to do so. Welcome, Audrey.

Audrey Kerr

Thank you for having me. I'm just going to take a few minutes to, I hope, give voice to what many of us have probably felt at this point in the journey. So I'll just say that I am a survivor and I just finished my last radiation treatment six days ago, so I'm just entering the other side of this journey. And so in June, I was diagnosed HER2-positive. I had two lumpectomies and that was followed by chemotherapy for three months and then a total of 30 radiation treatments that just concluded. And then of course I'll be continuing immunotherapy until August.

So that's what my course of treatment has looked like, and that probably sounds very familiar to many of you. As you can see, my hair is just starting to grow back and I haven't gone back to color yet, and I think I might stick with the gray. So we'll see what happens. I'm liking it so far.

In my own life, through a bit of serendipity, I connected with Sharsheret. And in my own life, I'm a professor. I'm a single mom to two teenage girls. I was an interfaith chaplain and in that work I did palliative care. So worked with a lot of people nearing the end of their lives. And also, serendipitously, as a professor, I'm an ethnographer, and the work that I do is called autopathography, which means I do work with illness narratives.

So I'd been very invested for a long time in collecting people's stories as they were dealing with illness. And the question I always ask is, how do we think about our lives differently or tell our

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

stories differently in the face of illness? So all of these worlds felt like they were colliding for me in ways that were obviously tremendously uncomfortable. But there was something I felt I could bring to the journey having worked with so many people who were dealing with serious illnesses.

So when I was first diagnosed, I felt nothing at all. I didn't feel sad, I didn't feel desperate, I didn't feel optimistic. I felt like I went through a very long period of about three or four months of just treading water, keeping my head above water. I felt nothing much at all except going through the courses.

And then of course I went from feeling nothing, not having an opportunity to process the illness, to feeling really sick during chemotherapy, which many people can relate to. And then that's a different type of treading water because you're just ... especially for those of us who are doing even a little bit of ... remaining at work. You're just trying to keep the family going, keep your children's heads up, helping your family and friends to feel optimism with you.

And on the other side of the physical sickness, there was this absolute fatigue, total exhaustion, emotional exhaustion, physical exhaustion. And then by the time the full exhaustion set in, that's when I found myself done with treatment. At no point in any of those four phases that went from feeling nothing to feeling sick, to feeling exhausted to being done, did I really feel that there was an opportunity to process all of what was happening. It's very quick and it almost happens upon you rather than in you or of you.

And so at my very last radiation treatment, I met this amazing ... It was a day when I really didn't feel like talking. And I happened to be sitting in the waiting room with this amazing older woman. And I closed my eyes that day, which I usually didn't do, but I just didn't feel like having a conversation that day. And she said, "Would you like someone to hold your hand?" And I accepted her offer.

And the next thing I knew, we were in this embrace that lasted such a long awkward amount of time that they told us they were watching us on the screen in the waiting room. And we just held each other and rocked for maybe, I don't know, three minutes, which with a stranger is an unusual amount of time.

And I realized in that moment, not only that I had not processed all of what had happened to me, but that I was feeling a deep sense of sadness that my experience was over having not had the opportunity to process it. I felt in that moment deeply sad that I would not see my radiation team

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

the next day. I felt a tremendous sense of loss, and I didn't want to ring the gong because I saw around me all of these people who were continuing on their journey and suffering.

The woman I was embracing was on palliative care. She was not going to make it. And so it felt as though just when I was beginning to feel that I could bear witness to and find words to speak to my experience, the palpable part of it was over. And that left me feeling not relieved actually, it left me feeling a bit sad.

I miss the folks from radiation. I miss seeing my team. I miss seeing my chemo nurses every week and laughing with them. And that longing is not a longing obviously for a treatment, but I think it's a longing for the safety of knowing that someone is watching your care and knowing that another set of eyes will be able to flag if something goes wrong.

So I just wanted to share or give voice to what I see as the four central ... what anxiety looks like for me that I think may resonate with some of you. First of all, the anxiety is the loss of your team. And that team includes the nurses, your doctors, organizations like Sharsheret that provides so much support, and feeling as though, the people who send you flowers in the beginning and meals, that all of that starts to fade away. And it feels as though you've become this free-floating entity and the discomfort of that.

The second source of anxiety is continuing to navigate the side effects of treatment when they're still as palpable as they were midway, but you're now doing it on your own. So for me, that's been neuropathy. It's been blurry vision. It's been achiness, the fatigue, some brain fog. I feel like sometimes I lose my words. And not having someone to check in with every week to say, "Hey, I'm still feeling this. Should I increase my gabapentin for my neuropathy?"

And then the third source of anxiety is life returning to normal when you don't feel normal. And for me, the fourth piece of it is the fear of reoccurrence and not the fear of reoccurrence in the breast, which I feel will be closely monitored. So that's not actually my fear. It's that there's that one cell that's migrated and it's migrated to a place where until it's far advanced there will be ... I'll feel fine if it's a bone cancer, for example, or another organ.

And so is it possible that not three or four years from now, but eight or 10 years from now when I still have young kids, 20-something kids, kids in their 20s, is it possible that there's somewhere that's not being monitored that I need to be concerned about? And how do I make sure that I'm giving voice to the proper concerns, that I'm voicing them to the right doctors, and that my doctors are

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

being aggressive enough and making sure that if I do have to go down this path again, that they're ahead of it. And I, by the way, should have said that I was stage one, so mine was caught very early.

And so I guess what I'll end by saying, I think most of us don't leave this with a feeling of being cured or even in remission, we leave with a feeling of unknowing. And giving space to acknowledging that feeling of unknowing and sitting with it, actually I think has tremendous value on our paths. So thank you for having me.

Thank you for joining us. Somebody just said they experienced almost everything you did and what you talked about resonated so much. So thank you for sharing your story.

Melissa Rosen

Thank you.

Our first presenter is Missy Petty. Missy is a licensed clinical professional counselor who provides individual and family counseling at Northwestern Medicine Living Well Cancer Resources in Warrenville, Illinois, which is outside of Chicago. Missy facilitates patient-based support groups in addition to running the survivorship program at Living Well.

As lead counselor, Missy provides oversight and coordination for Living Well's counseling and support programs. I do want to note, interestingly enough, both of our speakers tonight have amazing programs geared specifically to survivors of cancer. And the information for both of their programs, which are often available to people outside their specific geographic regions, will be in our follow-up email.

Missy earned a Bachelor's of Arts in sociology and her master degree in human services and counseling both from DePaul University. Missy, thank you so much for being here to help us sort out the often confusing emotions that surround cancer survivorship.

Missy Petty

Perfect. Thank you Sharsheret for having me. I do run the survivorship series for Living Well. And Audrey, a lot of what you shared is a lot of what we talk about in the survivorship series because I think unfortunately, your experience is so common, that survivorship feels clunky and awkward and not the place that people expect it to feel.

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

So I want to focus on talking about anxiety, specifically medical anxiety. And at the risk of giving you anxiety, here are a lot of screening questions about anxiety. But I think most of us have had the experience of being anxious or having anxiety in some kind of context. Whether it's giving a big presentation, or a job interview, a test, a first date, whatever, most people know what it feels like to be anxious.

But when we're talking about medical anxiety, especially within the context of a cancer diagnosis, we're not talking about anxiety that necessarily has an anxiety-inducing event, and then after that event starts or ends, our anxiety leaves with it. When we're talking about medical anxiety, we're typically talking about anxiety that lingers or a heightened baseline of anxiety.

And when we're talking about that within the context of a cancer diagnosis, that's with good reason. It's because anxiety is just baked into the cancer experience from beginning to end, and it is a healthy, appropriate reaction to a cancer diagnosis. You can feel anxiety when you're getting diagnosed initially, waiting for test results, waiting to see what your treatment plan is going to be, waiting to see if your treatment is working and waiting to find out your scan results, waiting to see how you'll feel on your treatment, waiting to see how you'll feel after treatment.

It seems to be part and parcel with the whole experience, and that's because there's so much uncertainty and so much waiting in the cancer experience that it's not a big surprise that anxiety is such a big part of it. We also know anxiety can increase feelings of pain, it can interfere with your ability to sleep, can cause nausea and GI symptoms, and just interfere with your overall quality of life.

And so when Sharsheret asked me to be part of this, and knowing, the survivorship series I run for Living Well is seven weeks long, so I've got a lot of ground and time to cover, I don't tonight. So I thought the best use of my time tonight was to give you guys some strategies to manage that anxiety when it really starts to feel like it's getting the better of you.

But before we get to that, there's a few things I want to talk about. The first is, and this is true in survivorship, but also for folks who are living with cancer as a chronic illness or who are newly diagnosed or in active treatment, is the bombardment of messaging about being positive, about having a particular outlook or mindset, and the importance of being positive, resisting stress, resisting anxiety.

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

What's interesting about that is that when we think about folks in the general population, folks who don't have cancer and who have what I'm sure seem like pretty trivial problems compared to a cancer diagnosis, they're not getting that messaging, right? Most people are not told how they have to be positive all of the time, and if they're not being positive that they're somehow inviting negative things into their life.

And yet, cancer patients who are going through what is truly an emotionally and physically distressing and difficult time are simultaneously getting this impossible messaging that they have to be upbeat all of the time, that they have to be positive to not make room for those dark or anxious thoughts, and it's just not possible. While being positive all the time is a wonderful ambition, it is not a fair or a realistic expectation.

And so what happens all the time, conversations I have in my office with clients, conversations I have in the survivorship series, are patients, whether they're in active treatment or in survivorship, feeling like they're somehow failing. They're failing in survivorship, they're failing as a patient because they're not upbeat all of the time. And that if only they would feel more grateful, more fortunate then they wouldn't be quite so anxious.

And we heard Audrey say that anxiety that you hit at the end of treatment, that's because you can't process something when you're in survival mode, and that's what going through treatment is. And so it's for most folks, not until they reach the end of their treatment that I always say time, space, permission, that they have the time, space, permission to start making sense of what just happened to them, of what they just went through. And then we start to see anxiety kick up.

And that's the same time that they're disconnected from their care and where everybody else in their life is ready for them to move on. We're over it. It's done. Why are we still talking about this? You should, all the shoulds start coming out. You should feel so fortunate. You should feel so grateful. You should feel so blessed.

And so what patients experiencing anxiety tend to do is they tend to retreat with their anxiety. They learn that whether it's their providers or their friends and family, that they don't want to hear it. And what we know about anxiety is that it grows in the dark. And so, one of the strategies I mention later on is just talking about it to a counselor or a support group because we know how much that can help.

The last thing I want to talk about before we get into strategies is the tightrope that we know patients are asked to walk. And so for most patients, whether it's during treatment or after treatment, they're being encouraged to pay attention to their body to look for changes. If you have a fever above a certain degree, if you notice symptoms or side effects or any of these kinds of feelings, something feels off or wrong, to make sure you're reporting that to your team.

And that's for a good reason, but what happens is that as a result, a lot of patients are paying a lot more attention to their body than they maybe ever have before. And it is easy in that space to teeter into this hyper-vigilance, where you had aches and pains before cancer that had nothing to do with cancer. You're going to have aches and pains after cancer that have nothing to do with cancer, but that gets harder to dismiss on the other side of that.

And so when we see folks having pinches, aches, pains, whatever, after a cancer diagnosis, not only are they in their hyper-vigilance assigning meaning to that, they're assigning this negative, nefarious, catastrophic meaning, right? My cancer has recurred, my cancer has progressed, it's everywhere, it's metastatic, I'm dying. And that anxiety is just like that.

The other side of that, and sometimes in response to that hyper-vigilance that we see patients do is almost detaching from their body. They're either not reporting because reporting makes it real, and it means something's got to get done, right? The doctor has to know, there's going to have to be a scan or there's going to have to be an appointment. And now this scary thing isn't just in your head anymore, and it's a reality. So folks either under reporting or folks really not wanting to be present in their body, where they don't take care of themselves as well because they don't want to pay attention to what they're feeling or they just start ignoring messages from their body.

And so I'm sharing that just so those of you listening, if you find yourself sometimes teetering between those extremes to just say that we know that that happens. And for as long as I've worked in oncology, I have never seen anyone walk that tightrope as nicely as this woman in this image is. Everybody teeters, and that's why I'm so glad Dr. Comander is here to talk to you guys about when to reach out to your care team and what to be mindful of. But just know that teetering between detachment and hyper-vigilance is really common.

I love this cartoon. I feel like they made it just for me because I think so many of us consciously or not seem to think that worrying about something is productive or it does something and it sometimes feels productive. I don't know if you've ever heard the expression that worry's like a rocking chair, that it gives you something to do, but it doesn't get you anywhere. And so we're going

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

to talk in a couple slides about how anxiety and worry and problem-solving look dangerously similar, but they are not the same.

So one of the first resources I wanted to share with you guys is one of my favorite anxiety worksheets of all time. I have this link in the corner here. There are so many wonderful resources on this website. They're all free. This particular worksheet is part of a chapter that's part of a larger workbook about challenging anxiety. It's also got some great one-sheets and workbooks about medical anxiety specifically.

But I like this worksheet because for folks who just cannot resist spending time with their anxious thoughts, we got to do it in an organized fashion. And while there is a lot of wisdom in learning how to resist the bait, learning how to delay anxious thoughts, most people find that really difficult. So if we're going to spend time with anxious thoughts, we're not going to just go straight down the rabbit hole. We're going to do it in an organized fashion. And I think this worksheet is such a great training tool for that.

And so this first part here asks you to just list what you're worried about, list your worrisome thoughts about that issue to pay attention to what you're predicting. Anxiety never predicts anything positive, so these are usually anxiety-inducing predictions. And then paying attention to what you feel as you're talking about that or writing that and to what extent you feel that.

And then some really important questions come. And so as you're listing what it is you're predicting or what you're worried about, this first question, what is the evidence for your prediction? When I ask clients this in session, the blank faces, I can't tell you how many times, because most of us don't challenge anxiety like that.

Anxiety presents with an urgency and a persuasiveness that's really easy to take at face value. Most of us don't push back and ask the questions. That's such an important question, what is the evidence for your prediction? Lots of times when I ask my clients this, there isn't any, but they've never thought to ask the question. Sometimes there is some evidence, and that's why that next question is so important, which is what is the evidence against my prediction?

While I think the whole worksheet is helpful, I always jump down to what is most likely. You'll see on the next slide that I call that the abbreviated version of the worksheet. What is it that you're worried about? What's the evidence that supports that? What's the evidence that goes against that and what is most likely?

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

And whether you are anxious about hosting a dinner party or parent-teacher conferences or cancer recurrence, I can't encourage you enough to bring those worries to a tool like this to give you the practice and the training to challenge those anxious thoughts rather than just taking them at face value.

Again, they're intimidating. They present with an urgency and a persuasiveness that's easy to buy into. It is a weird concept to tell you that you don't have to believe your own thoughts. We like our thoughts, we like to listen to them. But your thoughts, especially anxious ones lie to you. So this is a great tool for learning how to challenge those thoughts. And Melissa, I'm happy to send you a link to that and you can include that in the email that you send folks at the end.

You can see I mentioned the abbreviated version of the worksheet. Another tool that I have somehow become very well known for here at Living Well, even though I didn't invent this tool, is thought shifting or thought redirection. This gets talked about at Living Well as going grocery shopping in your mind, which is a weird thing to be associated with.

The premise here is that you can't think two things at the same time. You are welcome to try, but you can't. So the hope is to take the anxiety-inducing thought and replace it with an emotionally neutral time-consuming thought. So again, emotionally neutral or positive, if you can, time-consuming thought. Sometimes that looks like being in the waiting room at the doctor's office and counting the tiles on the ceiling.

This is my favorite tool for when you're anxious in the middle of the night and you don't want to turn lights on and you don't want to turn on a guided meditation or you don't want to start coloring. And so the way this looks, if I'm doing this at home is ... Don't use a Super Target, they're too big. Use a smaller grocery store.

If I'm doing this with my Trader Joe's, it means I'm envisioning everything that's in it. I walk through the first set of doors, there's the garbage cans where the kids' carts are, the baskets. I go through the second set of doors. There's the pallet with plants on it. There's the cut flowers. There's some potted plants and flowers. Then there's usually some promotional stuff in the middle.

As I'm thinking about all of those details, I can't hold onto any other thoughts, and that's the point. So whether it's grocery stores or album titles or whatever, taking your anxious thought and replacing

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

it with an emotionally neutral time-consuming thought to put some distance, we call that defusing, from your anxious thought and also giving your body a chance to relax from the anxiety that it's feeling.

I think an important concept with anxiety in general, but especially anxiety within a cancer context is the idea of unsafe versus uncomfortable. Anxiety messaging is that you are unsafe, that there is a danger, that there is a threat, and you need to get to safety. Well, this is really interesting when the thing that's threatening you is your own thoughts or your own body. How do you get to safety from there?

And so what's important here is remembering that although the messaging from anxiety is that you are unsafe knowing that you probably are. You're probably in your office or at home with your family or in a doctor's office where you are physically very safe. What you're not is comfortable. So you are not unsafe, you are uncomfortable. And, oh, yes, you are because anxiety is so uncomfortable. It is physically uncomfortable. It is emotionally uncomfortable.

But when we frame it as being uncomfortable versus being unsafe, it becomes a much more manageable issue. It's not unsafe and we have to figure out fight or flight, it's we are uncomfortable. And so the question becomes how can we get more comfortable right now? You're not unsafe waiting for scan results, you're uncomfortable. You're not unsafe in the doctor's office waiting to get your tumor markers, you're uncomfortable. And, oh, yes, you're very uncomfortable.

So what does comfort look like right now? How can you get more comfortable? Do you need to be still? Do you need to move? Do you want to be held? Do you want to be alone? Do you need to wrap yourself up in a warm blanket and watch a comfort show? Do you need to call a trusted friend? Do you need to color? And so when we take the problem and shift it from being you are unsafe, there's a danger, to you are uncomfortable, it becomes a lot easier to manage.

I'm known at Living Well for slides that make no sense if I'm not here to talk about them, and this slide is the perfect example. So the last concept I want to talk to you guys about, I call trusting your future self, which is why we have Marty McFly here with his hoverboard. And so I mentioned earlier how anxiety and problem-solving are not the same, and this is where we get into that.

And so if you're problem-solving, you have a clearly defined problem. A problem has the who, what, when, where, how to it, right? You can problem-solve from that place. You know you're in anxiety if you keep hearing the word if in your thoughts. What if this? What if that? And what if I wrote the

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

wrong date? And what if they say that? And what if I don't qualify for this? Or what if it shows something? You can hear yourself almost like a pinball bouncing around and lighting up all these different anxious places inside of you.

And so remembering, if you are in your anxiety, you cannot problem-solve, there's too many variables. Even if you're a person who thought there was a high likelihood that you would someday get cancer, there is no way that you knew in advance when that was going to happen, how that was going to happen, what the treatment protocols were going to look like, how you were going to feel on it, and how it was going to go. There's just too many variables.

And so there's two parts here. The first is if you find a thought that's troubling you or that you're spending a lot of time on, asking yourself the question, is this a problem? Is this clearly defined or is this anxiety? Are there lots of ifs here? If this is a problem, great, go into problem-solving.

If this is anxiety, that's when we got to go into that second part and recognizing that if, and again that word is if, your anxious thought were to become a problem three weeks from now, three months from now, three years from now, 30 years from now, at that point, you would have all of the information. But right now, today, the March 26th version of you doesn't have any of that information. You may never because this anxious thought or issue may never become an actual problem.

But if it does, a future version of you has all of that information and you've got to trust in that future version's ability to problem-solve, because your problem-solving skills so far have proven very capable. Whether or not you thought you were getting cancer, you didn't know any of the details, and you had to problem-solve all of that in real time as it was happening, and you did. I'm sure it wasn't any fun, and I'm sure that it was stressful, but you problem-solved in real time something you likely never thought was going to happen or you couldn't have predicted happening as it did.

And so you have to trust in your future self's ability to do that, that if your anxious thought becomes a problem, trusting in your future self's ability to problem-solve. And until it becomes a problem, letting it be something that belongs to your future self. I hope that makes sense. But again, asking yourself, is this an anxiety or a worry or is this a problem?

Some things you guys probably already know, but I'm just going to put up here on the screen because I don't want to be deficient in what I'm sharing with you. Guided meditation isn't on here, but ought to be because it can be very helpful. You'd be amazed at what you can accomplish as far

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

as reducing physical stress and anxiety in just five to 10 minutes of guided anxiety, gracious, guided meditation.

But coloring, journaling, talking with a counselor, support groups, aromatherapy, things like massage and Reiki, animal therapy, things like knitting, sewing, crocheting, woodworking, and I'd put coloring in there too. That ask enough of your attention that you can't spend time with your anxious thoughts, but not so much attention like reading where you're going to get frustrated. If you've ever tried to read when you're stressed or anxious, you get to the bottom of the page and you're like, "I have no idea what I just read." So things that require the right amount of your attention.

I know Melissa's going to share the worksheet. I may share with her my favorite link to a very basic guided meditation that she can share with you guys when this email goes out. And then also, like I said, the survivorship series for Living Well is seven weeks long, and we go over a lot of these things, but also a lot of the things that Audrey shared. It's a virtual program that anybody is welcome to join.

I'm mindful of the time. I want to make sure that Dr. Comander has the time to share what she needs to share, but just want to thank all of you for spending some of your evening with me and allowing me to be here.

Thank you so much.

Melissa Rosen

Perfect. Thank you. I saw people nodding. I saw some stuff in the chat. Yes, that resonated with all of us. So thank you. And while we know the anxiety and the emotional component of a cancer diagnosis, and specifically moving beyond doctor treatment is difficult and challenging to manage, the reality is there are some medical concerns that are important.

So I am going to temporarily say goodbye to Missy, and we are going to ask Dr. Comander to join us right now. Dr. Comander specializes in the care of women with breast cancer. She's the medical director of the Mass General Cancer Center in Waltham, Massachusetts, where she also serves as director of breast oncology and cancer survivorship at Mass General Cancer Center in Waltham, and at Newton-Wellesley Hospital. She's also an instructor in medicine at Harvard Medical School. She received her undergraduate degree and a master's degree in neuroscience at Harvard University and received her medical degree at Yale University School of Medicine.

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

Dr. Comander is known for her compassionate care and personal and passionate devotion to her patients and has a strong interest in improving quality of life and outcomes in cancer survivors through important lifestyle interventions including physical activity, diet, and mind-body interventions. She promotes healthy lifestyle for both her patients in active treatment and those in the survivorship phase of care. And to that end, she has launched a program called Paving the Path to Wellness, which is a 12-week lifestyle medicine-based survivorship program for women with breast cancer.

And again, as we're sharing the Living Well information, we will be sharing the Paving the Path to Wellness information. Dr. Comander, the floor is yours, and I know you also need to share some slides.

Dr. Amy Comander

Yes. Thank you so much, Melissa, for that kind introduction. It's so great to join you all tonight to cover this really important topic. I just want to start off by acknowledging Audrey's, really inspiring remarks at the beginning of this session tonight. I was taking many notes.

I always say I learn more from my patients than what I learned in my own medical school and medical training and all of that, because I remember congratulating my patient on her last day of chemo, "You did it. It's the last day of chemo. You're done. Hooray." And I'd have my patient look back at me and actually start crying and say, "I don't want to be done. I love seeing you. I love seeing my nurse. I love all the support I get every time I come here." And I see that as a very common theme, and I'm sure many of you can relate to that.

So Audrey, so many of the things you said really resonated with what I learn from my own patients every single day. And then Missy, your talk was also incredible. I was taking so many notes, learning so many helpful strategies from you for how to help my own patients manage their anxiety. So thank you so much.

We're going to talk about this topic of anxiety, and I'm going to skip through some of my slides since Missy really did such an amazing overview. But I did want to share this quote just at the beginning of this presentation, which I think will resonate with you.

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

"Every patient reacts a little differently, both biologically and psychologically after a cancer diagnosis. The only constant in cancer is inconstancy. The only certainty is a future of uncertainty, a truism for all of modern life, but one made vivid by life-threatening illness." And I think that really resonates with the topics we've already discussed this evening.

So I think we really talked a little bit about what we mean by anxiety. I usually like to start my talk just with a definition, and I think Missy outlined this beautifully in her talk, but really thinking about anxiety as a feeling of worry or unease and being afraid that something bad is going to happen.

And I think what I really want to highlight for those of you participating tonight is as a medical oncology community, we do care about this. We care about our patients who are experiencing anxiety. And as a community, we want to develop strategies to help identify this symptom in our patients and find ways to address this.

So this guideline was actually published just last year by the American Society of Clinical Oncology, which is the big national, actually international organization that most oncologists are part of. And I think I just share this paper just to reassure you that your medical team, the community of doctors and other healthcare providers really care about this topic.

And this was scouring the research on what does it show in terms of the best ways to help address this symptom and of course, help manage it. And I know it says adult cancer survivors. To me, that means individuals from the time of diagnosis and beyond, people who are being treated with curative intent, those in active treatment, and those who are living with cancer. Because we know due to all the amazing advances in my field, our patients are living for years with cancer diagnoses that may be advanced. And so I consider those individuals part of the cancer survivor population.

I also want to highlight this guideline, which is really exciting, which was also released last year, really a collaboration between ASCO and the Society for Integrative Oncology. Again, how can we identify symptoms of anxiety and depression and help manage these in our patients? And again, these papers are easily accessible online if you google them. Anyone can read them, you can look at the slides. So I'm not going through them in great detail, but I think it's just a great resource if anyone wants to take a deeper dive.

So I first want to acknowledge, and I think we all know this from the presentation from Audrey this evening, you are not alone. Anxiety is very common. And again, a definition of how anxiety refers to feeling nervous, on edge, or worried. And again, why do we feel this way? Well, we as humans have

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

evolved to develop this kind of symptom, I should say, this concept of anxiety or stress to help us respond to a threat.

And we evolved when we were running away from lions. So if one of us encountered a lion on the streets of New York City, we would have our heart rate go up, we'd start sweating, we'd get really scared and run, and that would be the appropriate response. But certainly, and that's outlined here, when we think about the fight or flight response, what is going on in our body when we are responding to a major stressor, fear, or something that's making us extremely anxious? And I think many of you can relate to the items here showed on this slide. Again, I mentioned heart beating faster, blood pressure going up, breathing more rapidly, sweating, etc.

Melissa mentioned in my intro that I am a former neuroscientist. I thought that's what I would be when I grow up, and maybe I still am at some degree. So I always love thinking about what is going on in the brain when we experience anxiety. And obviously this is a very simplistic slide depicting the brain, but there are changes occurring in our brain as well when we are experiencing fear and anxiety.

Certainly, our frontal lobe, which is processing stimuli in our environment, gets alerted and then sends signals to our amygdala, which is a part of the brain that mediates responsiveness to threats and other emotions. And that can then activate the hypothalamus, which tells the rest of the body to activate this fight or flight response. So thinking about how we manage anxiety is also how can we think of strategies to help our brain react better to these types of situations?

So I mentioned that anxiety is very prevalent and that's why we need to focus on this topic tonight. And certainly if anxiety is interfering with your activities of daily living, that's when additional support needs to be considered. And certainly we know anxiety itself can have adverse health consequences, making it hard for individuals to take care of themselves, maybe to comply with their medications, to get to appointments on time. It can also affect relationships. So there's many reasons why it's important for us to address this topic.

So I think we talked about a lot of these causes already of anxiety among individuals with a diagnosis of cancer. So I just wanted to highlight these here. Again, I'm not going to read the slide, but I think many of you would relate to things that I put on this slide. I think number one actually is fear of cancer recurrence. So I think we should leave some time this evening to discuss that specific topic, and certainly that was already highlighted tonight. And this concept that I hear from my patients all the time of scanxiety, like every time one needs a CT scan or a mammogram or even

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

a lab draw, there's this sense of fear that can arise when awaiting results. And certainly we can discuss some strategies to help address that too.

So just to touch on fear of cancer recurrence, which obviously is a major topic and we can talk about this more in the discussion, I want to acknowledge that worrying about cancer recurring is a normal thing to experience for cancer survivors. So acknowledging that is important. And I do think I like it when my patients bring this up with me so I can discuss this with them and strategies that they can use to help. And I think there are so many great individuals participating in this webinar tonight, learning from other cancer survivors who are facing similar stressors can be very helpful.

I think we learned many useful strategies from Missy in her presentation, but I do like to advise my patients to think about the things you can control, such as exercising, getting enough sleep, eating a healthy diet, et cetera. And again, thinking about self-care, what are things you can do to help you feel well and stay relaxed?

So again, we know this is like a roller coaster type of situation or a tightrope or whatever metaphor suits you. And I do think we discussed the number of these potential strategies in the previous talk, but again, thinking about this concept of mindfulness and meditation practices, that can be very helpful. Again, strategies from cognitive behavioral therapy, some of which we discussed in Missy's presentation. I love that helpful thinking diary for example, which was a great tip.

One thing I would like to point out, Dr. Google is not your friend. I think you would all agree with me on that one. And I try to encourage my patients to refrain from consulting him or her, because Dr. Google is often wrong and can spread misinformation and therefore can sometimes raise that anxiety level. So I would back off from that, but I know it's very difficult.

Finally, other adaptive strategies outlined here, gratitude, journaling, using humor, laughing with your family or friends, and again, getting sleep is so key. So a lot of these tips are from my colleague Dr. Hall, who has done a lot of work in this area.

Scanxiety, I touched on a little, and I'd love to hear from you about tips you have used to help address this particular concern. Again, I've outlined a few of them here. Some of them are very similar of course to other strategies that we can use to manage anxiety. But I wanted to highlight two at the bottom here that some of my patients have found to be helpful and I'm interested in learning from all of you, what's been helpful.

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

So first, this concept of the worry box. So take a box, you can decorate it if you want to or not, just a shoebox. And let's say you're really worried about that mammogram or you're really worried that you'll forget to get to that scan on whatever date it is or whatever it is that you're worried about. You can write it down on a piece of paper and put it in the box. So that worry, it's not going anywhere. You're not going to forget about it. It's in the box. And somehow writing something down and putting it in a box can sometimes help calm the mind and body and be a useful strategy.

Another tip is worry time. And some of my patients have found this to be beneficial. There's so many things to worry about. We all know this, right? And so maybe it's useful to set a time of day that you're going to let yourself worry about X, Y, or Z. So for example, in this example here, I'm going to worry about my upcoming scan from 6:00 to 6:15 PM. Then I'm going to make dinner and stop thinking about it. And if it starts to creep into my mind again, maybe I'll use some of these great strategies Missy outlined, or maybe I will call my friend and talk about something totally different. So again, worry time is another strategy that some of my patients have found to be useful. So I wanted to share that with you.

I did want to highlight here that again, the American Society of Clinical Oncology, our big organization, does recommend that all patients should be screened at their appointments for symptoms of anxiety and that patients, family, and caregivers should be given information and resources about how to address and manage anxiety. And this is really important and hopefully being done at your cancer center or doctor's office.

And then in terms of treatment, we've touched on a lot of these in the course of tonight's session, and they are outlined here. I just want to highlight a few, which I think are really key. Again, physical activity. I will note telling my own personal story, sometimes my job can get very stressful and I get very anxious myself, and I always tell myself, "Get up, go for that run. You will feel so much better."

And if you think back to my brain slide that I showed a few slides ago, there are changes in neurotransmitters, endorphins, and other pathways in our brain that get activated after physical activity and can really help change those circuits so you feel less anxious. So that's my personal strategy that works well for me, and maybe yoga or something else works well for you. But I really want to highlight the power of physical activity for helping address fear, anxiety, and stress.

We touched on support groups, which are key. Social connection is so important, and I definitely value that greatly for my patients. Referral to a mental health professional can be incredibly

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

important and therefore I want to highlight that. And then of course, in some cases, medication is needed. And if that is a concern, certainly your doctor can prescribe a medication for you or refer you to an individual like a psychiatry colleague, someone with expertise in psych oncology. There are so many different options out there.

Again, we talked a little bit about these mind-body approaches. I'm not going to go through these in great detail since Missy covered these so well. But again, these are very powerful and evidence-based, and they're actually included in those guidelines that I showed at the beginning of this talk.

Finally, these are just some great questions that you can pose to your healthcare team if you're wondering how you can get further support. Again, who can you talk to if you're feeling anxiety, depression, or other mental distress? What counseling services are available? Are there therapists available, a psychiatrist that you can see, or another colleague who can help prescribe medication to manage anxiety? So these are just lots of helpful questions that one can pose to their healthcare team if needed.

And finally, I did want to share some resources. Certainly Sharsheret is a great resource. Just the fact that this webinar is being held tonight is just a testament to the amazing support that this community provides. I will also refer you to cancer.net, which has lots of great resources out there and articles about managing stress, anxiety, how to find support and information, how to cope with the impact of cancer, mindfulness techniques, etc.

So I did speak really fast because I wanted to leave time for discussion, but I just wanted to thank you so much for the opportunity to join you today and I look forward to your questions.

Melissa Rosen

Thank you so much for that. Also amazing, amazing information. I want to note the time and I want to ask a few questions and then maybe we'll share the last couple of important points. And then if anybody wants to stay for a few more questions, that would be great. And just keep in mind that if you have questions still for any of our presenters, this is the time to put it in the chat box. But we got plenty beforehand, so let me just get started.

So I think this one specifically is for Dr. Comander, although in general, whoever wants to answer should answer. So the question here is, okay, I'm stressed, I know I'm stressed. How do I know when a symptom is worth calling the doctor for and when is it my anxiety? I happen to trip, but now

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

my back hurts longer than I thought it was supposed to. Am I experiencing pain from bone mets or am I being anxious and I sprained my back? How do we know when it's appropriate to pick up the phone?

Dr. Amy Comander

That's such a great question, and I feel like Missy did address this a little bit in her talk, and I want to hear her thoughts on this too because I loved how she addressed this. But I do think this is a very common situation. In fact, a patient told me today, she's like, "When I was first a year out from cancer, every time something went on, I was like, 'Oh my God, it's my breast cancer. Oh my God, it's my breast cancer.'" And she's like, "Every year that goes by, I feel like that gets a little bit better." So it was really great to hear her perspective on that. I think that's pretty true.

How do I counsel my patients? First of all, with Patient Gateway, that's what we use, and other ways to message your healthcare providers. It's a great way to reach out if you're having a symptom and you're just not sure if it merits a phone call or an appointment, and we're always available to help answer those types of questions.

It's a hard one to answer because obviously we want to be attentive to our patients if they're having a symptom. But I'm just going to use one example, like back pain. We all get back pain, picking up something off the floor and you just strain something or whatever might cause that. And obviously that happens all the time. It happened before breast cancer, it can happen after breast cancer or whatever diagnosis a person has.

So I usually tell someone, if it's really persisting more than 10 to 14 days and you really don't have a good explanation, then please reach out. Whether it's to me to your primary care, if you have a physiatrist, an orthopedist, whatever, reach out to one of us so we can help work it up further. But I think it's just important to recognize that we all get aches and pains and it's not always cancer. But I want to hear Missy's take on this, too.

Missy Petty

Well, I think you said it perfectly, Dr. Comander. And I think most patients are given similar advice by their physicians where it's like, "We're on the lookout for these specific things depending on your particular cancer and how we treated it. But also, if you have unexplained pain for X amount of time or any of these issues, we want to hear about it."

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

What I think can be helpful from the anxiety front is writing those symptoms down. Write the date down, write what it is that you're feeling. I'm having back pain. Where is your back pain? How bad is it on a scale of one to 10? And watch that over the next couple days because we are not usually great historians when we are anxious. Caregivers tend to be much better historians when we're having pain, stress, or anxiety, but they're not always with you and they're also not in your body.

And so making it so that it's less about you reflecting, right? I'm sure Dr. Comander, you see patients in your office and you ask how they are and they're like, "Oh, I'm fine." And their caregiver's like, "What are you talking about? You've been complaining about the stomach thing for two weeks."

So if it's a symptom that's concerning to you enough to generate anxious thoughts, write it down, write when it started, what you noticed, how intense it's feeling, and monitor that. And like Dr. Comander said, if in 10 or 14 days it persists, it's worth reaching out to your doctor.

Melissa Rosen

Thank you. That's perfect. Okay, a lot of questions that are a variant of how can I deal with my anxiety when and specific things. So a couple of them that came up. One is, I have symptoms, but scans and blood work show nothing. Or another one was, my doctor says that ongoing scans are unnecessary, but I'm not comfortable with that and how do I manage that?

A third one had to do with the fact that the doctor said, "There's nothing to do at this point. You'll know. You'll feel it if you have a recurrence. You'll have pain in your back, your head, whatever." And all of these things that negate the anxiety, "Nah, you don't worry about it, you'll feel it when it happens. I know you have symptoms, but we see nothing. I don't think the scans are as important as you do."

How do we deal with those realities and those responses that negate the anxiety we are feeling? And when is it important to stick up for ourselves and when do we cross that line into being a little bit difficult and whatever? You understand what I'm saying. Who wants to start?

Dr. Amy Comander

Oh, I mean, I just was going to say, first of all, no one's being difficult. I think my patients all the time ask me, "Can I get a PET scan? Can I get a CT scan, an MRI or whatever?" People want scans. I get it. We all feel reassured by having this test.

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

And if your doctor tells you, "I'm sorry, but a CT scan's really not indicated or whatever," there actually is research that supports on people who are asymptomatic that it really is not beneficial to do imaging studies. And I know you've all heard this and I know it's really hard to hear. I will also say that it's not always a good thing to get a scan if you don't really need it, radiation exposure, dye, allergies, kidneys, blah, blah, blah, all those things.

But let's say if you truly have a symptom that you're worried about that is persistent and unexplained, that is a reason to get a scan. So if my patient is having some kind of discomfort that's really persistent, like I said, whatever timeframe that is. If it's going on for more than a few weeks and she really doesn't have an explanation and we don't know what's going on, then of course we order tests.

So I don't know if that answers part of your question, but I think it's certainly important to follow up with a member of your team if the symptom is persisting and you feel that imaging is warranted and has not been ordered. So I think it's okay to be persistent if a symptom is persisting. I hope that helps address that.

Missy Petty

Yeah. You know what's funny? We've talked about scanxiety, and I've heard so many times from patients where they're like, "I have scanxiety," but also, "Can I get a scan every day? I would like a scan every day? That would be so reassuring to me."

And I get that.

And I totally understand that. And at the end of the day, I think there's two things that jump out to me. Most of your questions, they're a little different, but I think there's a common thread, and one is just about living with uncertainty because that's why they want the scan every day. They want the reassurance. That's part of why survivorship is so hard, because when you're going through cancer care, you're getting a lot of scans, you're getting your labs regularly, you're getting constant information about how your body is doing.

Then you finish treatment and they say, "See you in three months." And all that information dries up, and that's hard. And so living with uncertainty, doing the work in counseling or reading books or

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

listening to podcasts about how to learn to live with that uncertainty, because that's what it comes down to.

And then I also think it comes back to really feeling comfortable and having trust in your care team. Because like Dr. Comander said, if they're telling you, "We don't do the CA 125 for you," or, "We don't feel like it's a good indicator," or, "We don't do CT scans for this or whatever," they have a reason for that. And so when you have a trusting relationship with your physician, that's a lot easier to sit with.

If you don't feel like you're getting heard, if you don't feel like they're spending the time, then that's something worth looking into. And I've talked with patients who felt like they got exactly the care that they needed during treatment, but as they transitioned into survivorship, they don't feel like they're getting what they need from their physician anymore. And that's worth having a conversation with your doctor about, where it's I'm anxious, I need to better understand the reasons for this.

Melissa Rosen

Yeah, absolutely. And that's why programs like both the ones that both of you run and organizations like Sharsheret are so incredibly important because survivorship is another stage of the cancer experience. It's yes. So that's important. Okay, we do have some more questions, but it is already after 9:00.

So once again, I want to thank both Dr. Comander, and Missy. I want to thank Audrey for all sharing their experience, their expertise, their passions. I hope you found this presentation as impactful as I did. Of course, thank you again to Daiichi Sankyo, Merck, and the Cooperative Agreement 19-1906 from the Center for Disease Control and Prevention.

As we conclude this evening, and I still have a couple more thoughts I want to share, but as we conclude this evening, I am putting a link to a survey. Oh, it's there twice now. A link to a survey, thank you, Bonnie. An evaluation survey, it will take just two minutes and you can click that and do that now and still listen to the last couple of moments of the webinar.

I want to remind you that Sharsheret's Thriving Again survivorship kit, which was created with the support of the CDC is an important, a free, and a customized resource. It doesn't matter if you're still currently in treatment, a recent survivor, or a long-term survivor, or if you're someone facing

Beyond Cancer: Managing Medical Anxiety

March 26, 2024

Sharsheret: The Jewish Breast and Ovarian Cancer Community

metastatic cancer, there are resources for everyone on many, many of the issues we spoke about tonight, we deal with as survivors, including fear of recurrence and the scanxiety.

And there will be an opportunity to request your Thriving Again kit as part of the evaluation. That is another reason to go on and evaluate. And that's the link again. And of course, I want you to remember that Sharsheret's social workers are there for you to answer questions, connect you to resources, listen to you vent, provide support. And you can reach our team through the contact information that is in the chat box right now.

So thank you so much. Be on the lookout end of this week, very early next week for a follow-up email that will include information about Missy's program, the Living Well program, Dr. Comander's Paving a Path to Wellness program, as well as the anxiety worksheet that Missy shared, a link to our survivorship kit, and of course, a link to the transcript and the recording of tonight's webinar, which will include the slides.

Thank you all so much for joining us, and have a wonderful evening. Good night.