The Big Ordeal:

Coping with Cancer Emotions

National Webinar Transcript

March 3, 202

Presented by:

SHARSHERET®
The Jewish Breast & Ovarian Cancer Community

Presented in Partnership with:

CANCER SUPPORT COMMUNITY.

WOMAN TO WOMAN

Melissa Rosen:

Thank you so much for joining us. My name is Melissa Rosen. I want to thank everyone for being here today for an important conversation about managing cancer emotions. Before we begin, I have a few housekeeping details I'd like to share. I want to thank our program partners on this important webinar, all fantastic organizations that we have worked with to accomplish our shared mission. The first is Woman to Woman, a now national support program for those facing gynecological cancers founded at Mount Sinai in New York City, and Cancer Support Communities, a network of 175 locations, including Cancer Support Community and Gilda's Clubs that provide support to those impacted by any cancer.

Melissa Rosen:

This webinar is being recorded and will be posted on Sharsheret's website along with a transcript, but as always, participants faces and names will not be in the recording. All participants were muted upon entry, please keep yourself on mute throughout the entire program. I do want to say that we received so many important and insightful questions ahead of tonight's program. During the Q&A period, you'll notice that many of the questions were combined, so be sure to listen for your question and not your exact words. For any questions that arise tonight during the program, please enter them into the chat box, which you can of course access at the bottom of your screen.

Melissa Rosen:

Any questions we don't get to tonight because there were so many will be addressed over the course of the next week. As a reminder, Sharsheret has been providing telehealth services to the breast and ovarian cancer communities for 20 years now. I recently heard someone describe this as a time of creative connection, and I really do believe that's true. As we continue to provide the necessary support we always have, we found meaning in the creative ways we've connected with all of you during the past year. We truly are an online community. A reminder that in addition to the many formal programs to help women and their families navigate different aspects of the cancer experience, our clinical social workers are available for one-on-one support.

Melissa Rosen:

They can answer questions, connect you to appropriate resources, and help you process the emotions that often arise during the cancer experience and so much more. An additional source of support is our Sharsheret Facebook groups. We now have three distinct groups; Sharsheret Support for anyone facing breast or ovarian cancer or a high diagnostic risk from stage zero to three. Our Embrace community is our group dedicated to those facing advanced or metastatic cancer. And launched just this week, our new Caregivers Facebook Community for caregivers of anyone directly impacted by breast or ovarian cancer or heightened risk.

Melissa Rosen:

And as always, our support services are 100% confidential and 100% free. Now, as we move into the webinar itself, I need to remind you that Sharsheret is a national not-for-profit cancer support and education organization and does not provide any medical advice or perform any medical procedures. The information provided by Sharsheret and by our speaker is not a substitute for medical advice or treatment for a specific medical condition. You should not use this information to diagnose or treat a health problem. As always, seek the advice of your physician or qualified health provider with any questions you have. Okay, let's get to it.

Melissa Rosen:

I am so excited to have Cynthia Hayes with us tonight. Cynthia has been preparing her whole life to write this book, The Big Ordeal: Understanding and Managing the Psychological Turmoil of Cancer. She learned the basics of interviewing and synthesizing information, finding headlines, and telling stories as a journalist early in her career. After earning her MBA at Harvard Business School, she spent 25 years as a management consultant. In that role, of course, she depended on her ability to jump into new topics, ask sensitive questions, and turn complex findings into a compelling narrative.

Melissa Rosen:

Shortly prior to her own diagnosis, Cynthia resigned from Montefiore Medical Center, where for three years she had served as VP and chief marketing officer, focused on telling stories of health and recovery. While at Montefiore, she gained a deeper understanding of medicine and an opportunity to build relationships with cancer professionals who helped her to write The Big Ordeal. Cynthia, welcome, and I turn the program over to you.

Cynthia Hayes:

All right. Well, thank you so much for that wonderful introduction and for inviting me to come and speak with this important audience. Let me just see if I can make the screen sharing work and hopefully you can see my slides. Are we good?

Melissa Rosen:

Yes, we are good.

Cynthia Hayes:

All right. So, The Big Ordeal. As Melissa just mentioned, I am a survivor, I am not an oncologist or a psychotherapist. So what you're going to hear from me today is based on my experience as a journalist, hospital executive, cancer patient, advocates, and volunteer, and most importantly, based on my own emotional journey through cancer. People always ask me, "Well, why did you write The Big Ordeal?" I was really surprised when I was diagnosed at how isolated I felt in that diagnosis. I was surprised also with the emotional volatility, the ups and downs, the extreme emotions that I felt as I was first accustomizing myself to that diagnosis and then what it meant to have that diagnosis and what I was going to have to deal with going forward.

Cynthia Hayes:

I was really surprised by the lack of conversation that my medical team offered, despite the fact that my medical team were involved in founding Women to Women, and so they recognized in general the need for emotional support for people going through cancer. But still there was no conversation around it. It was really only after the fact that I discovered how common the emotional experience of cancer is and that there are so many resources and tools available if we know to ask for. Well, so I set about writing this book in the hopes that we can elevate the conversation around the emotional experience of cancer and hopefully allow people to tap into some of those resources earlier in the process and feel less uncomfortable with the fact that cancer is an emotional experience.

Cynthia Hayes:

So when I set about to write this book, I started talking with all sorts of people, initially friends, and then friends of family and friends of friends and slowly expanding the network until I had interviewed more than 100 people, mostly in the US but also in other English speaking countries. I spoke with cancer patients and with cancer caregivers, I spoke with men and women, young and old, newly diagnosed, long ago diagnoses, breast cancers, central organ cancers, blood cancers, really tried to get as diverse a perspective as possible to know, well, what is the common experience? And it was as I was learning that there was in fact a common experience that I wanted to understand why.

Cynthia Hayes:

That's when I started speaking with experts in psychology and oncology, exercise physiology, even neuroscience, just to try and understand what the heck is going on here and why do we all feel this way as we go through cancer. The bottom line in all of this is that cancer is emotional, and it's emotional because of a variety of different forces that really gang up on us when we have cancer. Let's start with those external forces. There are centuries of history where cancer was a death sentence, millennia really where there was no cure for cancer and if you received a cancer diagnosis, you knew that your days were limited. That's no longer the case, but that fear of cancer is so baked into our culture and our experience that as soon as we hear the words, "You have cancer", we have this visceral reaction that, "Oh my God! I'm going to die."

Cynthia Hayes:

That sets us up for a whole chain of events that we'll talk about down the road. There's also an implied sense of responsibility. We don't necessarily feel responsible if we find out that we have a heart valve defect and need to have some plumbing work done, but we often feel a sense of responsibility for our own cancer, which is an unfair sense of responsibility given that we all know people who smoked three packs a day and never had to worry about cancer, just as we all know people who have taken care of themselves from the very beginning and everybody would say, "But you're so healthy and you eat right all the time," and still they develop cancer.

Cynthia Hayes:

So there's this strange sense that somehow we need to control our own cancer and that we are in control and responsible for our own cancer that contributes to the intensity of that emotional response. Unfortunately, there is a continued stigma around mental health issues in our culture as well, so we're not comfortable admitting that we need help, admitting that we are depressed, admitting that we are overwhelmed or feeling anxious or stressed by the experience, and that dual stigma of the cancer diagnosis and the mental health issues makes it really hard to address this. Add to that the fact that there's a very good chance that when you have a cancer diagnosis, you are being treated by a doctor you've known for about a minute.

Cynthia Hayes:

Maybe the doctor that diagnosed you, as in my case my gynecologist, who delivered my babies who are now 27 and 30, she's the one who said, "Cynthia, you flunked your Pap smear, I think you have cancer." But she wasn't the one who was going to treat my cancer. So my oncology team, they were brand new to me, so I didn't have the same sort of rapport with them that I had with a doctor that I've known for 20 years. And this is so often the case, that we just don't necessarily have the same sort of relationship with our care team that would allow us to feel comfortable to own up to some of our emotions.

Cynthia Hayes:

Add to that the whole complexity of the diagnosis process, that there's an inkling of a diagnosis and then there's maybe a confirmation of that diagnosis, but we still have to go through additional testing or biopsies or whatever until we know exactly what type of cancer it is, exactly the stage that the cancer is, how aggressive that cancer is, and what the treatment is going to be. And all of that involves uncertainty and waiting and therefore an opportunity for that anxiety to grow. Then the last force that I think is really instrumental is that our medical care team has gotten so specialized that often the doctors view us as a host for the cancer that they need to remove, as opposed to a person who is suffering with this disease.

Cynthia Hayes:

It's sort of baked into the way our medical system works now that there's a specialist for everything, and that just contributes to the kinds of conversations that we might or might not be having with our medical team. But there are a lot of things going on inside that also contribute to our emotions during cancer. The first is that there are some cellular changes, physiological changes that are driving our emotions, starting with inflammation and a class of proteins called cytokines. Cytokines have been in the news recently because of COVID, but cytokines are proteins that allow our immune system to communicate to itself.

Cynthia Hayes:

So you get a paper cut on your finger and somebody has to tell the platelets to get down to your finger and fix that paper cut. That's what cytokines do. We have pro-inflammatory cytokines and anti-inflammatory cytokines, and they're supposed to stay in balance. When the pro-inflammatory cytokines have let out their signal and the platelets come and the white blood cells come and they take care of that paper cut, then the anti-inflammatory cytokines are supposed to send out signals to, "Okay, calm down. Everything's under control." Well, often with cancer, those cytokines get out of balance.

Cynthia Hayes:

They get out of balance because, well, the paper cut causes a little pro-inflammatory cytokines. Just imagine what a major surgery does. It turns out that cancer cells, when they die off, cause inflammatory cytokines. Chemotherapy, immunotherapy, in fact, some immunotherapies are actually cytokines being infused into your system. Radiation causes pro-inflammatory cytokines. Well, that's all great because that means that they're helping us to get better, but they also change our brain chemistry. One of the things that inflammation and pro-inflammatory cytokines do is they tell the brain to sort of, "Let's check down, let's climb under the covers, let's hide. We're not well."

Cynthia Hayes:

So we get stuck in this pro-inflammatory cycle where our brain is getting the signal to shut down and that makes it really easy for us to get depressed and we have to actually take steps to counter that and make sure that we get ourselves undepressed because of those cytokines. We also undergo a lot of hormonal changes. If it's a gynecologic cancer and you are thrown into instant menopause, or maybe you are post-menopausal, but they take out those ovaries and that last little trickle of estrogen is no longer there. Maybe it's breast cancer or prostate cancer and you are being given estrogen or androgen suppressants as part of your treatment.

Cynthia Hayes:

Those have enormous impacts on how our brain functions as well as how our body feels. Even dexamethasone and other steroids, which are often part of the pre-meds when we're getting chemo, will really take us for a wild ride. I was always surprised, on the fourth day after my infusion, when I would have an absolute emotional crash and be a bundle of tears all day long, well, I never realized that the steroids that they had given me on chemo infusion day and the day after that would help prevent any sort of allergic reaction and help increase the effectiveness of the chemo, it took them a little bit of time to get out of my system, but when they were out of my system, my body was saying, "Hey, wait a minute here, guys. I liked the dexamethasone."

Cynthia Hayes:

So I would have this big emotional crash, and nobody ever told me that you feel like crap this day, but the next day you're going to feel fine because your body's adjusted to no longer having that. So there's a lot of stuff going on in our bodies, not to mention the stress and fatigue that are with us throughout the entire cancer experience that really can drive the emotional volatility. And we care about that emotional volatility because, first of all, we don't feel good if our emotions are up and down and all over the place, but also because our emotions influence our physical health. They can get in the way of our ability to... or our desire to adhere to our medical treatment.

Cynthia Hayes:

They actually influence things like the experience of pain and other side effects and can contribute to our ability to survive a difficult cancer. They get in the way of our daily lives. We have to carry on our lives, whether we feel up to it on any given day or not, and meeting our work at home and social obligations really depends on being able to manage and deal with our emotions, and of course meeting our work obligations and financial obligations so that we can maintain our insurance coverage so that we can pay for the next treatment, is also really important. So we care about emotions not just because they color our experience, but because they can directly influence our physical health.

Cynthia Hayes:

What I learned in all of my conversations is that in fact there's a somewhat predictable pattern of emotions that cancer patients go through. We know that at diagnosis, we're going to feel a certain level of stress and anxiety, We know that as treatment builds, we're going to feel a little more depressed, a lot more fatigued, begin to lose a sense of self. So we know that those patterns exist, we don't necessarily get told that in the beginning of our treatment experience. But in hindsight and reading the literature and talking to patients, it's very clear these patterns exist. But of course, we're all different, and so we express those emotions differently.

Cynthia Hayes:

The emotions can vary in intensity, they can vary in timing, and they can vary in how willing we are to communicate those, or even allow ourselves to feel those emotions. And all of that is influenced by who we are as people before cancer as well as what happens during the particular cancer experience. So your DNA, your personality, your experiences growing up, everything that happens to you up until that moment when you hear you've got cancer is going to influence how you respond. Then once you have cancer, your prognosis and your fear around that prognosis, how much pain you're in, the medication you're on, the treatments that you're taking, the side effects of your cancer, all of that also influences the intensity and actuality of your experience.

Cynthia Hayes:

Then of course, it's also influenced by how much you understand about your cancer, what your rapport is with your care team. So, just as no two cancers are really alike, no two cancer patient experiences are really alike, and yet we have so many similarities at the same time. So what does that cancer emotional journey look like? The main thing I want you to see (on this chart) here is that fear and stress and anxiety stayed with us throughout the entire experience. Over on the left, we have diagnosis through testing and monitoring, we have a regression and progression, and end of life module in the middle, and then should we be able to skip over that module and get to end of treatment and physical and emotional recovery on the other end?

Cynthia Hayes:

There are a great deal of similarities throughout this even though we all may experience it slightly different. Let's start with diagnosis. For most people, a diagnosis comes as a shock. Now, there are some situations where that's not the case. So for instance, if there's a family history of breast cancer and you've been getting tested and checked and had multiple biopsies, sometimes you even hear that diagnosis as a relief, because finally, now I can deal with it, you were anticipating its arrival for so long. But for most people, cancer doesn't really have any clear symptoms, and so it comes as a surprise. For me, I flunked a Pap smear.

Cynthia Hayes:

I was feeling perfectly healthy and then went in and got a phone call saying, "Nope, you're not well," Elliot, he thought he had cracked a rib at the gym. He went to get a chest x-ray and then was told that, "No, you actually have cancerous lesions in your lungs. It's metastasized melanoma." Maura went into the hospital thinking she was having surgery for fibroids, and she's in the recovery room with tubes down her throat, and the doctor says, "No, you've got ovarian cancer." I mean, it's much more likely that you're going to be shocked by your diagnosis and that element of surprise contributes a great deal to the stress and anxiety and fear that we all experience at the time of diagnosis.

Cynthia Hayes:

From that diagnosis, then we have to move into decision-making mode and we have to decide, who do we want to be our care team and what protocol do I feel comfortable in conversation with my doctor about moving forward with? For so many people, the stress of making that decision is just overwhelming. In large part, we have to absorb so much information at a time when our stress levels are already high. And when our stress levels are high, it plays with our brain and it plays with our fight and flight instinct and we want to run away from this rather than sit and digest it and be rational about it, which makes it really hard to make that decision.

Cynthia Hayes:

Eventually, many people feel like they have to sort of flip into hyper activity mode where they have to schedule tests and go meet doctors, and when they're running, running, running trying to beat the clock against their cancer, and all of the time, their stress and anxiety is increasing. As one patient said, "I really felt like I had to get from zero to PhD in a matter of weeks." It's not always easy to do that. Sometimes, a doctor will guide you and say, "This is the best doctor for your type of cancer, get an appointment here."

Cynthia Hayes:

But often, the diagnosing doctor will recommend a doctor that you don't like or will recommend a protocol that you don't feel comfortable with or will sort of throw up their hands and say, "I don't know anything about your particular type of cancer. I don't know how to help you." So people have very different experiences at the time when they're being asked to make that decision. They also have very different circumstances. So if for instance you have breast cancer, you have to think through not only what am I trying to deal with here in terms of getting the cancer treated, but do I want to have reconstruction and what other decisions do I need to make at the same time?

Cynthia Hayes:

Or perhaps you are a young woman having a diagnosis at a time where you need to think through fertility issues before you can start treatment. Or perhaps it's impossible to find a doctor who actually knows something about your cancer because you have such a rare disease. So there are a lot of complications that can add to that stress at decision-making time. If we're lucky, we get some good guidance and are able to make it through. But this is where personality and life experiences really begins to differentiate us as well. One patient, Brian, he grew up in Ireland during the struggles and he was used to having to make decisions fast. His dad's shop got blown up a couple of times, his mom's office shot out a couple of times.

Cynthia Hayes:

He was used to, okay, hit the ground, move, make a decision fast. So when he was diagnosed with blood cancer, his response was, "Okay, what do I need to do? Let's make a decision. Let's moving on." And that was just a very different experience from Dawn who was diagnosed with breast cancer and she just could not get her arms around the idea of having reconstructive surgery and yet didn't want to go flat. She spent two months going around in circles before she could get comfortable enough with moving forward. So again, all different ways of approaching it all influenced by our past experiences and our emotional makeup.

Cynthia Hayes:

Once we begin treatment, we often feel some sense of relief that, okay, finally, somebody is dealing with my cancer, but we also tend to feel incredible sense of isolation, nobody could possibly understand what I'm going through, and a loss of balance in our lives, a loss of sense of control over our lives, because we have to submit to the cancer protocol, whatever that might be. So starting treatment is a really mixed bag for a lot of people as they try to figure out, how do I make this work for me and who am if I am a cancer patient? As we continue with treatment, that's when we really begin to see a whole confluence of emotions.

Cynthia Hayes:

Fatigue is a part of just about everyone's cancer experience, and it can be really overwhelming for so many patients. This is when the cytokines can begin to drive us into depression when we begin to feel that fuzzy thinking, foggy brain that leads to a sense of cognitive impairment. It's where for a lot of us, we have an identity crisis because we don't look like ourselves, we don't feel like ourselves, our brain is not functioning the way we were used to it functioning. So you sort of look in the mirror and say, "Who am I anyway?"

Cynthia Hayes:

There's a real sense of helplessness that begins to build in here because we have been so dependent on so many people for our care and for maintaining the home and for supporting us as treatment goes on that we lose our sense of hope and sense of self that we are going to be able to get our lives back. Testing and monitoring is a really hard time for a lot of people, stress and anxiety and fear just go through the roof for many of us. Our bodies betrayed us once, there was a cancer growing and we didn't know. So when we go back in for whether it's a blood test or a Pap scan, or MRI, a mammogram, whatever it might be, we instantly have that renewed sense of fear that we're going to hear the same bad news over again. And it takes such a long time to lose that sense of fear.

Cynthia Hayes:

There was one patient I spoke with who said that she plotted her CA-125 markers for five years logarithmically. CA-125 is a cancer antigen for a lot of gynecologic cancers. And of course, there's nothing magical about that number. Many doctors will tell you, "Well, so long as it's in a roundabout range, so long as the trend is in the right direction, that's all we can expect from it." But she was so anxious about the possibility of recurrence that every time that the test needed to be done, she would put herself scotch, sit down, have that first sip of scotch, then log into the hospital website, download her results, take another sip of scotch before she could look at those results, and then put it on logarithmic chart and see, well, am I headed in the right direction? Is it okay for me?

Cynthia Hayes:

I really didn't speak to anybody who didn't have some sense of anxiety around that testing. If in fact we progress or have a recurrence, this is when emotions tend to get very, very high. Often, we feel anger at the world, at the medical team who may have promised that we were going to be cured, at ourselves for not being able to deal with this, and incredible sadness that, well, I went through all of that, I asked my friends for support, I was so dependent on everyone for so long, how can it be that I have to go through all of that again? So progression and recurrence is a really hard time for many patients.

Cynthia Hayes:

And of course, it doesn't always move towards end of life, but when it does, we see a great deal of frustration. We often see patients experiencing guilt again because they feel like they didn't do enough to prevent their cancer from coming back, they didn't do enough to take care of themselves and keep themselves alive for their family. That's when worlds begin to collapse on patients and when we see the emotional gap between patients and their loving caregivers begin to increase as patients and caregivers are not necessarily on the same page about what's happening and what needs to happen as a patient begins to wrap up his or her life.

Cynthia Hayes:

If in fact were able to recover from cancer and we're lucky enough to actually see an end of treatment, sometimes that can be a really challenging time for patients because this is when patients experience a huge sense of loss. The caregivers and friends and the rest of the world thinks, "Well, okay, you're done. You're back, everything's fine." But you're not back and you don't feel well and you don't feel like yourself. But meanwhile, you've been cut free from your medical team, nobody's looking at you, nobody is monitoring you every day. So there's this incredible sense of fear, but also a sense of loss because you don't know who you are anymore or where you are and how are you going to get back to your own life.

Cynthia Hayes:

Eventually, we recover physically, and that physical process can take 12 to 18 months after treatment ends for those cytokines to get back into balance, for our scars to heal internally and externally, for our bodies to sort of resume homeostasis and feel much more akin to what they were like before cancer. However, we've probably spent much more time being couch potatoes than we would normally have been. So even if we are physically recovered, we're not back to who we were pre-cancer. It takes even longer to rebuild the strength and stamina both physically and mentally before we can say that we are physically recovered.

Cynthia Hayes:

Then that emotional recovery really only comes after we finish the physical recovery. And during that emotional recovery, we see a lot of different things going on for patients. Sometimes, we see people looking for the silver lining where people are trying to find some benefit that came out of their cancer experience. People begin to accept their new normal. Other patients, they just want to forget it all quickly, put it in the past, and ignore it and move on with their lives without ever trying to get to any sort of emotional closure, but just say, "You know what? Enough already. I'm done." So that's the typical sequence of emotion.

Cynthia Hayes:

But again, everybody's a little bit different. Everybody experiences it differently and everybody expresses it differently. But the most important thing to keep in mind is that we all cope in different ways and the variety of coping mechanisms allow us to manage the stress and get through our daily lives, they are as varied as we are, and they tend to evolve throughout the process. There isn't one fixed experience and that coping mechanism is the only one we're going to use and that's what's going to help us every single day. There are so many different ways to cope. Often, we rely on ourselves first of all, but then friends and family, online, and in before times, actual live in-person peer support and professional intervention.

Cynthia Hayes:

And it's just so important. I mean, you folks are so lucky to know that Sharsheret exists, that Cancer Support Community and Women to Women exist and offer these incredible free support opportunities for us. I wish I had known that at the start of my cancer experience. I really had no idea about these things, and all of these resources are so important to us. So how do we cope with cancer? Some of us cope by doing and we get very fixed on making sure we're sleeping well, making sure we're eating well, making sure we're exercising regularly. We try to socialize and get in appropriate amounts of laughing and hugging or we journal and write our experiences and we try very consciously to focus on a sense of purpose and an expression of gratitude in our lives.

Cynthia Hayes:

But that's only one way of coping. Another way of coping is to cope more in our minds by trying to solve problems and prioritize, by trying to reduce our stress and minimize the number of things we need to deal with on any given day, by trying to contain the problem to make it more manageable, by finding distractions, by taking it one day at a time. A third major category of coping is mind-body coping. Prayer and meditation and mindfulness are real important in that group as are things like acupuncture and acupressure, massage, that really connect us to how we think and how we feel about coping. Yoga and progressive relaxation, guided imagery, these are all great ways of coping.

Cynthia Hayes:

We just have to make sure that we're not coping too well, that we're not doing all of these things and putting a nice smiley face on while inside we're really still hurting. I mentioned that because that's what I did. I was projecting, as my doctor says, this bad-ass image that everybody thought that I had it under control. But I didn't have it under control and I would let it all out in the shower and that's the only place that I allowed myself to cry. So we all have different ways of coping and we all have different ways of expressing those emotions, we just have to be really tuned into what works and doesn't work for us and make sure that we're being honest with ourselves about what we're really feeling.

Cynthia Hayes:

It's so easy to project strength and sometimes it seems easier to project strength because I don't necessarily want to break into tears if the doorman asks me, "How are you doing today?" So I need to put a little bit of a shell around me. If a friend I haven't seen in 10 years asks, "How are you doing?" I don't want to devolve into a puddle on the sidewalk, so I put a little bit of a veneer there. But I have to be honest with myself so that I can be honest with those that I'm closest with and with those that can in fact give me support. So that's a hard balance for us all to strike.

Cynthia Hayes:

I want to talk specifically about exercise and its role in coping because it has been proven to reduce stress and improve mood and support a healthy immune system. One of the ways it does that is actually by signaling the body to balance out those cytokines. So whether it is a simple going for a walk or doing aerobic training or weight training, any type of exercise can really help here. It helps by not just making you feel better, but there's been studies that show it reduces recurrence, it can speed your recovery, and it can really help with managing side effects, particularly neuropathy and lymphedema which so many of us suffer with.

Cynthia Hayes:

So you need to check with your doctor about when you can start exercising and what type of exercise might be appropriate and you need to move slowly into or back to a level of exercise that you were comfortable with before cancer. But just know that there are so many places that you can tap into to exercise that can really help you; Sharsheret, Moving for Life, MSK, Memorial Sloan Kettering has a mind-body workshop, all great resources for you. The last thing I want to talk about it... I know that there are a lot of questions, so my apologies we're running longer than I intended.

Cynthia Hayes:

But I want to talk about the special challenges to intimacy. And I don't just mean sexual activity, I mean intimacy, I mean closeness with the people that you love and that you hold dear. There are challenges, both emotional and physical challenges, to intimacy that make cancer particularly hard for both maintaining loving relationships and maintaining physically active relationships. The first is that, because of all of the emotions, we often allow distance to grow between ourselves and those that we love and that love us. We allow that distance to grow because of our fear and our stress and our own difficulties in expressing what we're feeling. We also often want to protect our loved ones.

Cynthia Hayes:

I thought this was particularly telling. I told my mother, who now is 95, that I had cancer at the time of my diagnosis, but I didn't tell her all that I was going through. It wasn't until she actually read my book that she said, "Cynthia, I don't think I gave you enough support when you were going through cancer. I'm sorry about that." And I thought to myself, "How could she have known?" Because I never told her how much support I needed. So I had to tell her, "You gave me all of the support that I asked for. I didn't ask for all of the support that I needed." I think that's so typical of us, particularly us women who are used to being the super copers, to managing the household, to doing anything for our dearest friends that they need.

Cynthia Hayes:

So we think of ourselves as being the one who cares for others, not the one who needs care. That concern for how our partners may view us, how other people may view us, prevents us from being honest both with ourselves and with others. Add to that we may not feel as comfortable with who we are going through cancer as we would normally feel. And we may also feel like, "I've been so dependent on my family and friends, how can I ask for one more thing?" So we withhold again some of our needs. And of course, time gets in the way as well. We are so busy taking care of ourselves and cancer we don't have a chance to actually sit down and have the conversation and open up about what's going on.

Cynthia Hayes:

If you add to that the physical challenges of fatigue and hormonal changes and the sensational changes due to scarring and neuropathy, all that happens with surgeries and drains and ostomies and losing body parts and whatnot, the physical side of intimacy becomes that much harder, whether we are in a committed long-term relationship or whether we are dating and trying to establish a new relationship. The emotional and the physical interplay is just so great that it's a challenge and it can take months or years to feel comfortable with who we are both physically and emotionally in order to open up to partners, be they older or new, about our readiness for physical intimacy even if we have that emotional intimacy.

Cynthia Hayes:

So how do you deal with all of this? The advice from those who have been there is pretty consistent that we need to accept it and own it and do our best to manage it. And I think that that's particularly important advice for all of us to hear. We like to live in denial, and for many of us, denial is a great coping mechanism. It's just, "Hide my head in the sand, I'm not going to accept that I have cancer. I'm going to do what the doctor says, but I'm not going to own it." Well, by not owning it, we can't actually manage it and those emotions come back to haunt us later on. Another consistent piece of advice was, one step at a time, how do you eat an elephant one bite at a time?

Cynthia Hayes:

I mean, constrain the problem enough so that you can manage it on a day-to-day basis. It's also important to recognize that it is going to be full of ups and downs and you have to be prepared to roll with it; and some days, it's going to be easier to roll with it and other days it's not. So you have to feel how you feel on any given day and not anticipate that, "I'm going to feel this way and I'm going to be able to do that," because you may not. So it really is a question of... as one patient said, "Nobody expects you to be super woman. Go with what you need, with what feels right, but don't sit in a place of despair." Cancer is challenging and you need to get the help that you need in order to get on with your life.

Cynthia Hayes:

One of the ways that you can get that help is by asking a lot of questions and asking for the help. So I always encourage people, just ask, just ask. Do you have a question for your doctor? Just ask. And it's important that you think about advocating for yourself with your medical team because your doctors are the experts in cancer. But you are the expert in you, you are the only one who knows what it feels like to be inside your body right now, what it feels like to be inside your mind and your soul, and so you have to be advocating for yourself and saying, "But doctor, why do I feel this way? How can you help me feel better? I know you're curing my cancer, but what can you do for my anxiety?

Cynthia Hayes:

I can't possibly get in that MRI tube unless you give me something for my anxiety. How can you help me?" So, ask. But also ask your friends for help. So many cancer patients said, "I felt like I was overloading my friends." And often, friends have had enough of us by the time where we're done with our cancer. But you know what? A good friend will be there even if you've already asked that they take your child to afterschool five more times, even if you've asked a neighbor to bring over dinner 10 times already. You needed an 11th time? Ask for it and you can be sure your true friends will be very happy to be able to give that to you again.

Cynthia Hayes:

Get the support you need. There's so much support out there. If you need professional support, get it. If you need antidepressants to get through your day, ask for it. If you need help getting to sleep because of your anxiety, ask for it. And if your oncologist isn't able to help you, ask for a referral to somebody in supportive care who can. And don't be turned off by the name. Sometimes it's called palliative care, sometimes it's called supportive care. Palliative care doesn't mean hospice care, it doesn't mean end-of-life care. To palliate is to ease, to make better. So palliative care is all about the supportive care around the oncology care in the middle.

Cynthia Hayes:

We often get turned off by the terminology or think of ourselves as being weak because we need to ask for it. Ask for the support you need, you'll feel so much better. As we discussed at the beginning, it'll help you get through your cancer treatment and therefore adhere to the treatment and have a greater chance of recovery. Another thing is really to be gentle and loving and patient with yourself. You need to be good to you and you need to understand that only you know the right way to cope. You need to love yourself and know that you are doing the best that you can for yourself. And that's hard.

Cynthia Hayes:

Sometimes, those around us don't understand what we need. Sometimes, those around us lose patience with us because we're still needy. One patient I spoke with, at one point, her husband said, "What the F! Why can't you just get well already?" Clearly, he was exhausted from taking care of the kids, running the household, keeping the income up to pay for all of her care. And it had been eight months of dealing with a very aggressive type of lymphoma and he had had enough. But she still needed him and she still needed his support and she still needed other people to care for her and to give to her. So she needed to find the strength to say, "I'm sorry, I can't get well any faster than I can."

Cynthia Hayes:

So that's my advice to you, to know yourself enough physically and emotionally to know that the only right way to cope is the way that works for you.

Melissa Rosen:

Oh, gosh! Cynthia, thank you so much. That was just so meaningful. We'll pick a few questions, but any questions that aren't answered, we're going to find a way to get that information to you as part of a follow-up email. So if not tonight, hang tight and we'll get to you soon.

Melissa Rosen:

One of the questions that came in... and when I say one, I melded several of them. So most of these, several people asked. But can you please elaborate on the relationship between pre-existing depression and anxiety and emotional fallout from cancer? In other words, how do we distinguish a side effect of our situation or our treatment from a pre-existing condition?

Cynthia Hayes:

I think that's a really excellent question. And of course, it doesn't matter whether it existed beforehand or whether it came as a result of the cancer, if you're feeling anxious, if you're feeling depressed, it's a side effect right now and it needs to be dealt with. And so, it's hard to pull those things apart. I think for those of us who tend to be anxious, our anxiety is going to be heightened, for those of us who tend to be depressed, our depression is going to be exacerbated. So it doesn't really matter what the starting point was, what matters is, how are we feeling right now as we're going through cancer, and therefore, what do we need to deal with in order to get better?

Melissa Rosen:

That makes a lot of sense. I appreciate the way this question was worded - somebody asked, "Why am I so angry with my doctors, my friends, my family telling me what I should do with my body?" And then other questions chimed in, "How can I set aside my fears and those emotions, including that anger, to make clear treatment decisions and stick to them?"

Cynthia Hayes:

Yeah. The latter half of that question is very tricky. Let's start with the first part of that question. Anger is such a natural response. I mean, just the injustice around cancer. This one smokes and doesn't get cancer, I got cancer, I exercise. I mean, the injustice of it makes us angry. We get angry when doctors get it wrong. They say, "Oh, you're going to be fine. You're going to be fully recovered after we do this surgery or you get through this round of chemo or whatever," and then the cancer comes back. We get so angry. There was one gentleman I spoke with who had a type of thyroid cancer.

Cynthia Hayes:

He had two thyroid cancers at once and they treated what they thought was the extent of his thyroid cancer only to discover that he had this other rarer type of cancer that was hiding. He's a minister, he preaches about the goodness of God, and here he was, he was so angry and he was so betrayed by his God that he was railing against his God when he found out that he had this incurable type of cancer. Anger and rage are a common experience in cancer. I think the best thing you can do is punch a pillow and go out to the woods and scream and just let it out. It is justifiable.

Cynthia Hayes:

And it's important to express that rage because you do have to shift gears, you do have to make decisions that you can feel comfortable moving forward with. And I think in general, we need to allow ourselves the full expression of our emotions, whether it is sadness or anger or depression before we can actually clear the mind enough to get into that decision-making mode. And it's tricky. I mean, some people can make that switch because... like Brian, one I mentioned earlier, they're trained in, how do I quickly make a decision and move forward? Others of us belabor our decisions and never feel comfortable.

Cynthia Hayes:

I had one friend who was diagnosed with a second cancer and it was a rare type of gynecologic cancer. She went back and forth for almost two months trying to decide, do I go with this doctor who wrote the protocol for the disease or this doctor who has an understanding mannerism and will follow the protocol? She didn't know which was going to work for her because she was so fearful of her diagnosis. It took her a long time to accept that she needed to just make a decision and move forward and that both of them were going to be good doctors because they were both going to follow the right protocol. Ultimately, she chose to work with the doctor that made her feel good as opposed to the doctor who made her feel anxious.

Cynthia Hayes:

In the book, I talk about how we make gut decisions versus labored decisions. Think about the first time you were learning to drive a car and trying to make the decision consciously each time when you step on the gas pedal or the brake in order to maintain proper distance between you and the car in front of you. But we don't have the opportunity to train for a cancer decision, but we do have other experiences that help us train for flipping the switch from an emotional decision to a rational decision, and that's what we have to rely on with cancer.

Melissa Rosen:

That makes sense. Okay. Like I said, we're going to ask two more questions and then the rest we'll address later. So, many people asked for recommendations, very practical recommendations, for coping with the ever present fear of reoccurrence.

Cynthia Hayes:

Yeah. I think that that fear of reoccurrence is one of the hardest emotions to deal with, because our bodies have betrayed us, and so we are no longer confident that the cancer isn't going to come back; it was there the first time, we need to know about it. It is like PTSD though, where we sort of need to do a certain amount of exposure therapy in order to reduce that fear. So each time we go and get a test and the test results comes back with good news, that helps to reduce our fear for the next time and the next time and the next time. So, that exposure therapy allows those over time, well, it does take time, to control that fear and anxiety.

Cynthia Hayes:

But that said, if the fear and anxiety is getting in the way of you getting that test and knowing those results or being able to relax enough to get on with your life in between those tests, then it's time to get some professional support for your anxiety.

Melissa Rosen:

That's good advice.

Cynthia Hayes:

Some people find that exercising really, really helps with anxiety, and high intensity exercise in particular, because it gives you those endorphins that helps to counteract the power of anxiety. But exercise is not everybody's thing, so acupuncture is also really good for helping with anxiety, unless you have needle anxiety, in which case don't try it.

Melissa Rosen:

Okay. Cynthia, I don't know if you see what's coming in on the chat box right now, but so many people have commented about what an honest and engaging presentation... Validating, somebody says right now. I want to thank you for sharing your experience, your insights. Personally, I found your presentation fascinating, practical, and as a cancer survivor myself, comforting. So I hope you did as well. I once again want to thank our program partners on this important webinar. Remember, in addition to the book, which is available on Amazon, several people asked where they could get it, support is available not only at Sharsheret, but at Women to Women and Cancer Support Communities and other organizations.

Melissa Rosen:

The book is called... somebody just asked, The Big Ordeal by Cynthia Hayes. Oh, there it is. Right now, the Cancer Support Community website is on there, is in the chat box, and we're going to get the Woman to Woman for gynecological cancers up there as well. I want to ask as we finish up I have put a link for a brief evaluation in the chat box. You can click that and still listen to what we're saying now and fill out the evaluation because the evaluations really do impact our future programming. And I'm actually really excited to announce that anybody who fills out an evaluation tonight will be entered in a raffle to win a personalized, autographed copy of the book, The Big Ordeal.

Melissa Rosen:

One last reminder that we are here for you through this time, through this time of COVID, and through this time of your cancer experience. We provide one-on-one support and other programs to help you navigate the cancer experience. All are completely free, completely private. You can email us at clinicalstaff@sharsheret.org. Again, our social workers are there for you. My last thing that I want to say before I say good night is that we have an array of exciting webinars coming up and planned over the next few weeks and few months.

Melissa Rosen:

So please check out our website regularly to see what topics are coming up. I will tell you that by the beginning of next week, we will send you a follow-up email with a link to the recording and transcript and send answers to the questions that did not get asked tonight. Again, take a moment to fill out that. Thank you, Cynthia, and have a wonderful evening. Good night.

Cynthia Hayes:

Goodnight, all. Thank you so much. It was a pleasure to be here.

About Sharsheret

Sharsheret, Hebrew for “chain”, is a national non-profit organization, improves the lives of Jewish women and families living with or at increased genetic risk for breast or ovarian cancer through personalized support and saves lives through educational outreach.

With four offices (California, Florida, Illinois, and New Jersey), Sharsheret serves 150,000 women, families, health care professionals, community leaders, and students, in all 50 states. Sharsheret creates a safe community for women facing breast cancer and ovarian cancer and their families at every stage of life and at every stage of cancer - from before diagnosis, during treatment and into the survivorship years. While our expertise is focused on young women and Jewish families, more than 15% of those we serve are not Jewish. All Sharsheret programs serve all women and men.

As a premier organization for psychosocial support, Sharsheret’s Executive Director chairs the Federal Advisory Committee on Breast Cancer in Young Women, Sharsheret works closely with the Centers for Disease Control and Prevention (CDC), and participates in psychosocial research studies and evaluations with major cancer centers, including Georgetown University Lombardi Comprehensive Cancer Center. Sharsheret is accredited by the Better Business Bureau and has earned a 4-star rating from Charity Navigator for four consecutive years.

Sharsheret offers the following national programs:

The Link Program

- Peer Support Network, connecting women newly diagnosed or at high risk of developing breast cancer one-on-one with others who share similar diagnoses and experiences
- Embrace™, supporting women living with advanced breast cancer • Genetics for Life®, addressing hereditary breast and ovarian cancer
- Thriving Again®, providing individualized support, education, and survivorship plans for young breast cancer survivors • Busy Box®, for young parents facing breast cancer
- Best Face Forward®, addressing the cosmetic side effects of treatment
- Family Focus®, providing resources and support for caregivers and family members
- Ovarian Cancer Program, tailored resources and support for young Jewish women and families facing ovarian cancer • Sharsheret Supports™, developing local support groups and programs

Education and Outreach Programs

- Health Care Symposia, on issues unique to younger women facing breast cancer
- Sharsheret on Campus, outreach and education to students on campus
- Sharsheret Educational Resource Booklet Series, culturally-relevant publications for Jewish women and their families and healthcare Professionals

Disclaimer

The information contained in this document is presented in summary form only and is intended to provide broad understanding and knowledge of the topics. The information should not be considered complete and should not be used in place of a visit, call, consultation, or advice of your physician or other health care Professional. The document does not recommend the selfmanagement of health problems. Should you have any health care related questions, please call or see your physician or other health care provider promptly. You should never disregard medical advice or delay in seeking it because of something you have read here.

The information contained in this document is compiled from a variety of sources ("Information Providers"). Neither Sharsheret, nor any Information Providers, shall be responsible for information provided herein under any theory of liability or indemnity. Sharsheret and Information Providers make no warranty as to the reliability, accuracy, timeliness, usefulness, or completeness of the information.

Sharsheret and Information Providers cannot and do not warrant against human and machine errors, omissions, delays, interruptions or losses, including loss of data.