Frankly Speaking about Cancer: Why Can’t I Stay Positive?

National Webinar Transcript

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Presented by:

SHARSHERET®
The Jewish Breast & Ovarian Cancer Community

About Sharsheret

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

With regional offices in the Midwest, Northeast, Southeast, West, and Israel, Sharsheret serves 275,000 women, families, health care professionals, community leaders, and students. Sharsheret creates a safe community for women facing breast cancer and ovarian cancer and their families at every stage of life and at every stage of cancer - from before diagnosis, during treatment and into the survivorship years. While our expertise is focused on young women and Jewish families, approximately 25% of those we serve are not Jewish. All Sharsheret programs serve all women and men.

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

Sharsheret offers the following national programs:

The Link Program

Peer Support Network, connecting women newly diagnosed or at high risk of developing breast cancer one-on-one with others who share similar diagnoses and experiences

- Embrace™, supporting women living with advanced breast cancer
- Genetics for Life®, addressing hereditary breast and ovarian cancer
- Thriving Again®, providing individualized support, education, and survivorship plans for young breast cancer survivors
- Busy Box®, for young parents facing breast cancer
- Best Face Forward®, addressing the cosmetic side effects of treatment
- Family Focus®, providing resources and support for caregivers and family members
- Ovarian Cancer Program, tailored resources and support for young Jewish women and families facing ovarian cancer
- Sharsheret Supports™, developing local support groups and programs

Education and Outreach Programs

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

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 self-management of health problems. Should you have any health care related questions,

Melissa Rosen:

My name is Melissa Rosen. I want to thank you again for joining Sharsheret for an important conversation about positivity and cancer. Before we begin, I have a few housekeeping items to share. I want to thank our sponsors for today's webinar, which enable us to continue offering such meaningful programs. Thank you to ASI, GSK, Merck, CGEN and the Siegmund and Edith Blumenthal Memorial Fund. Of course, I want to thank our collaborating partner, Cancer Support Community, for working with Sharsheret to enhance support to all those impacted by breast and ovarian cancer.

This webinar is being recorded and will be posted on Sharsheret's website along with a transcript. Participant's faces and names will not be a part of that recording. I do want to say that we receive a good number of really important meaningful questions through the registration process. As questions arise during today's presentation, please use the chat box. We will address them during the Q&A at the end of the webinar.

As a reminder, Sharsheret has been providing telehealth services to the breast and ovarian cancer communities for 20 years because cancer is so much more than simply a physical experience. In addition to our many formal programs to help women and their families navigate different aspects of the cancer experience, I want to remind you that our clinical social workers are available every day, every weekday from 9:00 to 5:00 in every time zone for one on one support. They can answer questions, connect you to appropriate resources, allow you to vent on a particularly difficult day and so much more. As always, and as with every one of our services, these are completely free and completely confidential. As we move into the webinar itself, I also want to remind you that Sharsheret is a national, not-for-profit cancer support and education organization and does not provide any medical advice or perform any medical procedures.

The information provided by Sharsheret, by today's 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 and always seek the advice of your physician or qualified healthcare provider with any questions you might have regarding your condition. We are so very fortunate to have our speaker with us today. Kelly Hendershot is a licensed clinical social worker and is the Senior Director of Program at Cancer Support Community. She serves as the Lead Liaison for Patient and Family Programming across Cancer Support Community's growing network of affiliates and healthcare partners.

She ensures that programming is effectively implemented throughout the network and meets the quality standards that are a part of their 40-year tradition as a relentless ally for patients. Prior to joining CSE, Kelly was the Program Director for Gilda's Club Quad Cities. Kelly has said, "What began as a need for support through my husband's cancer diagnosis and death grew into a strong passion of ensuring that others never have to face cancer alone." So you know that she is absolutely dedicated to her mission. Kelly, the screen is yours.

Kelly Hendershot :

Thank you, Melissa. So I'm happy to be here today to be talking about this. Why Can't I Stay Positive conversation. I think it's probably all resonated with all of us at one point in our lives. We just need to be real with our feelings, but somebody around us is wanting us to stay positive. So we'll be diving into that. But just real briefly, I wanted to share the mission of Cancer Support Community. So like Sharsheret, we are a nonprofit. We're a global organization whose mission is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community.

So we are headquarters here in Washington, DC. I'm out of my home office with you today. But we have 50 markets across the globe. So we're primarily in the United States and Canada, but have some outreach around the globe as well. We offer educational programs, support groups, healthy lifestyle activities, social connection opportunities, and much, much more, to anyone who's impacted by cancer. So the person diagnosed, family member, friends all the way through bereavement.

Just have a few disclosures for you. These slides were created by the Cancer Support Community. We have an award-winning educational series called Frankly Speaking About Cancer. This is one of those toolkits that is put together for psychosocial support reasons. But this content was developed independently with some outside review from psychosocial experts. CSC, our organization had final control over all the content that you will see in this program. Again, I am from our headquarters location. When you hear CSC, you often hear Gilda's Club, but we are all one happy family organization. Our affiliates either go by the name Gilda's Club or Cancer Support Community.

So just to give you an overview, I'm going to do a little bit of stage setting. We'll be talking about depression and cancer, grief and cancer, resilience and cancer. Then of course, just provide you with some resources and have plenty of time for some Q&A. We will be using polling features throughout this presentation, just so that there's a little bit more active engagement. I know we get a little zoomed out just watching somebody on a screen.

So to go ahead and set the stage a little bit here, I am going to you be starting with a poll in just a moment here. But the topics we're really talking about, and these are universal challenges when living with cancer, there's unwanted aloneness, financial burden, loss of hope, loss of control, and then living with uncertainty. Amy, if you could go ahead and launch our first poll today, just want to know today. As you're watching this webinar, which of these really resonates most with you today?

A lot of quick responses coming in, this is great. We'll see if we can get up to 75, we're just about there. I think we might have hit our well. Amy, I don't know if attendees can see the results. Is there a way to share that?

Amy:

They should be able to.

Kelly Hendershot :

Okay. So as you can all see then, there is just a wide variety of feelings, these different challenges that everybody's resonating with today. A lot of living with uncertainty and wanting aloneness. Of course, there's always that financial burden, loss of hope and loss of control.

Amy:

Okay. I think now people can see, if anybody wants to share it in the chat. If you can see the results now. Perfect.

Kelly Hendershot :

Great. Well, that was just to get and do some level setting to see how we're all feeling today. So we can go ahead and proceed with the slides and stop sharing the poll. This next slide that I have up comes from our cancer experience registry. It's a tool through cancer support community that's been developed by our research and training institute. What it does is it provides a forum for anyone impacted by cancer to share their voice about issues that matter to them. It helps them connect with each other and ensures that their experiences are communicated to a broader cancer community.

The goal is to really make a difference in how people move through their cancer journey. So this data comes from our 2020 registry. It's just the top 10 concerns across the entire registry that people had. You can see eating and nutrition is up there pretty high. Cancer progression or coming back, worrying about the future and what lays ahead. These are all different things that are going to come into play with how positive we're feeling, negative or positive, or how positive we're portraying our feelings during a cancer diagnosis.

I just want to highlight here a few stats from that registry report, 49% of our respondents were at risk for clinically significant levels of anxiety. Likewise, 38% of respondents were at risk for clinically significant levels of depression. So it's important to note, this is saying that they are at risk. We do not do you any clinical diagnosis of anxiety or depression. But as you can see, it's not uncommon at all for somebody who's impacted by cancer, whether they're the patient or the caregiver, to have these feelings of anxiety and depression.

Some more interesting stats for you. 49% felt that their anxiety was worse than the national average. 34% reported that their fatigue was worse than the national average. 39% said that their health was somewhat worse or much worse than before they began a caregiving role. So this is what we're hearing specifically from caregivers. So very similar stats on the caregiver side as from the person diagnosed side. It really can take a great toll on health for the caregiver if they're not addressing their own physical and mental needs during a loved one's cancer diagnosis.

I once had a participant in a support group say that they had been having some vision issues and heart issues. They just kept putting off their doctor's appointment. When you do that, it's understandable. You want, as a caregiver, devote all your time as you much as you can to the person with the diagnosis. But when you're putting off your own needs, you're joining that 39% who say that their health is worse or much worse than became a caregiver. If you're not addressing some of these health needs in the immediate future. When your loved one really needs you, if there's a progression, if they get to a point where they're in an end of life or hospice situation, then you're going to probably wish you had taken care of yourself so that you had that energy at those critical times.

Again, that living with uncertainty, 53% of our cancer experience registry respondents indicated that they're worried about the future and what lies ahead. So that means putting plans on hold that fear that the treatment will stop working or that it won't work. There's a lot of uncertainty that comes into play here. I just want you to think a little bit about what on this slide resonates most with you. What depletes your resources? Is it unmanaged distress, untreated depression, unrecognized grief, limited social support? Just take a moment to think about which of these resonates both with you today. I keep saying today because I realize our feelings change so frequently when we're experiencing cancer.

So I've already said the word distress several times. You're going to hear me refer to it several more throughout this presentation. But what I'm talking about distress, I'm talking about a mix of anxiety and depressive symptoms. They may cause things like sleepiness, loss of appetite, trouble, concentrating, difficulty carrying on regular activities. We know that some level of distress is normal. But about a third of cancer patients experience, significant distress, only about 5% of those with cancer obtain psychological help though for this distress. So while distress doesn't affect the cancer itself per se, it does affect how patients and caregivers cope with cancer.

It can also impact the ability for somebody to follow up with treatment recommendations. So we know that distress has predictable points, when the diagnosis first happens, when there's a treatment decision to be made, when a scan is coming up. It causes that anxiety, feeling of anxiety. Then of course, anytime there's a progression with cancer. So this next tool that I have up on the screen, it's just a little brief glimpse at our Cancer Support Source distress screening tool.

So this is something that we use to just gauge at it. It's a snapshot of time. It could change tomorrow depending on how you're feeling, but we use it to kind of identify immediate distressors in somebody's life, whether they're the patient, the survivor or a caregiver.

So I'm going to have Amy share our next poll here. What I'd like you to do is while you're looking at the questions on this screen and just grab a piece of scrap paper and think about how many you would consider as being moderately to very seriously concerned about. So we'll go ahead and give you a moment to fill this out. Again, we can't see who's submitting what. We can't even see what you're responding to. We're just looking at ranges of numbers. We'll share the results in a moment here once a few more people have a chance to respond. I know it's a lot to think about.

Looks like we slowed down quite a bit. Amy, you can probably go ahead and share those response. You're on it. So not surprising, nobody answered none. We are all feeling some sort of distress in our life, which is part of why I used this slide to help normalize the conversation. But you can see that there's a wide variety. Again, this tool is a snapshot in time. So this is how you you're currently feeling in an hour. You could take this and it could look slightly different depending on what happens between now and then. But I think that gives us all, just illustrates the point that we all carry distress with us when cancer is in part of our lives. I think we can stop sharing and move on with the slides.

All right. There's going to be several points throughout this presentation where I just like to remind you, if you are having health concerns that you want to talk to your doctor, make sure that you're asking for support and resources that you can use in the community that you're located in.

All right. So the burden of positive thinking, I know you can all read this for yourself, but I'm going to read it anyway. It's bad enough to have cancer. But when all your family and friends are saying that you have to be positive, and you have to fight this thing, and the patient is exhausted and beaten up by treatment, it seems to me that adding that burden to be positive is just ridiculous.

So I think this is again, you're all here for a workshop called Why Can't I Stay Positive. So this has definitely impacted you in some sort of way. There's a lot of different myths and worries that cancer patients and caregivers have, that negative thinking can cause recurrence. It can cause progression. But there's really no evidence that shows high level optimism prior to treatment enhanced anyone's survival rate. So encouraging patients to be positive might only add to that burden of having cancer while providing very little benefit. this came from a study of patients with a non-small cell carcinoma. But you can't take care of yourself if you're trying to stay positive for everybody else around you.

So what's so burdensome about trying to stay positive all the time? It's the fact that it provides an inability to acknowledge that cancer is difficult and frightening experience. It takes away that fear from us, but not in a good way. Fear is something that we need to work through and deal with.

There's that insistence that you have to always put on a happy face for the people around you. When you're the one who has the cancer diagnosis or you're perhaps the caregiver whose loved one has this diagnosis, being positive gives that feeling of guilt because you're unable to always be positive. There's just a wide range of emotions that people seem to think are unacceptable. So trying to compound all this along with your cancer diagnosis can be really difficult and unrealistic.

So what we're going to do is just take a few moments here. I'm going to look at my watch and give you a few minutes to reflect. In your experience with cancer, have you ever felt pressure to think happy, put a smile on your face or find silver lining in all of this? So just think about what that's looked like for you in your own life for a few minutes.

Melissa Rosen:

Could you please repeat the reflection one more time?

Kelly Hendershot :

The reflection is just, have you felt pressure to think happy, put a smile on your face or find a silver lining in any of this? While you're all still thinking about that, I'm going to have Amy go ahead and launch another poll.

So this is just asking you, how often do you feel pressured to think positively about you or your loved one's cancer diagnosis? I'll give people just another moment to answer.

Amy, it looks like it's slowed down. We can probably go ahead and share the results. So some of you always feel this pressure, a lot of you often or sometimes. A few rarely's in there, but nobody has acknowledged that they never feel this way. So it is something that's a bit of a constant, whether we're the person with a cancer diagnosis, a caregiver. I'm sure we have some people on the call here today who are bereaved due to their loved one dying from their cancer are. So we can go ahead and stop sharing and move forward.

We're going to be talking about depression next. So we all face depressive moments in our life. To diagnostically be diagnosed with depression. You have to be experiencing five or more symptoms of depression during a two-week program or a two-week period of time. At least one of these symptoms would either be of depressive mood, a loss of interest or pleasure. So some of these symptoms are you're depressed most of the day, nearly every day. You're remarkably diminished. You have little interest or pleasure in things that you used to.

There could be significant weight loss when you're not dieting or on the opposite end, significant weight gain. A lot of us choose to cope through eating, I'm one of those. A slowing down of thought and a reduction of fiscal movement that others in our lives can also observe. Another sign of depression is a fatigue or loss of energy nearly every day, feelings of worthlessness or excessive and inappropriate guilt, nearly every day, recurrent thoughts of death or recurrent suicidal ideation without a specific plan or suicide attempts.

Then to receive a diagnosis of depression, these symptoms must have called clinically significant distress or impairment in your social, occupational, or other important areas of your life. So these symptoms also are not a result of substance abuse or other medical conditions. So it can be a little bit difficult to diagnose. The main thing to remember here is that only a licensed mental health professional or a medical professional on your care team can diagnose you with depression. So if you think that these symptoms are frequent and relevant, please be sure that you're talking to your healthcare team about them more.

But again, I mentioned that all of us have felt depression at some point in our life, even though we're not necessarily clinically diagnosed with it. So we're going to talk a little bit about how it feels. There's mood related symptoms, feeling sad, hopeless, irritable, numb, worthless, and down. There's physical symptoms related to depression, just to show that it's much more than mood related. It can cause fatigue, appetite loss, insomnia, which is when you're not able to fall asleep and stay asleep, hypersomnia which is feeling very sleepy most of the time throughout your day. It can even lead to sexual problems or lower sexual desire.

There's behaviors affected by being depressed. So again, it's that loss of interest and activities that you usually enjoy. It can be frequent crying, withdrawal from family and friends, loss of motivation for your normal daily activities. Then there's the cognitive symptoms. So in extreme situations, these may include thoughts that life's not worth living or thoughts of even hurting yourself. They would be persistent thoughts. So it can also cause memory problems, just trouble focusing and making decisions that were usually easy to make, and then just experiencing a lot of negative thoughts.

So we know that it's common to feel depressed. In fact, one-third of cancer patients report a mood disorder at some point after diagnosis. With the first year after diagnosis, this is when it poses the greatest risk. Then between 10 and 20% of cancer patients continue to report depression and anxiety after the initial stress of diagnosis or recurrence. More than half of cancer patients and survivors report fatigue as being an ongoing issue. A large number of survivors continue to struggle with pain and isolation. So again, if these are things that you are feeling on a persistent basis, make sure that you're talking to your oncologist, your primary care provider, your oncology, social worker, nurse navigator, someone to that effect about your mental health concerns.

So again, knowing that this is a common occurrence, we also know that depression can impact quality of life. It can decrease adherence to cancer treatment. If you're having trouble just getting out of bed for the day, it's logical to think you'd have trouble getting yourself to a doctor appointment. It can lead to longer hospital stays. 38% of respondents said that they were substantially worse levels of anxiety than the national average. 26 reported that they had substantially worse levels of depression than the national average.

So again, tell your healthcare team about any of these concerns and ask them for support and resources. That can include individual counseling medications, joining a support group. There's a lot of different ways that we can address depression.

Another thing we know about depression, it's treatable. So it can be treated in a lot of different factors. Many patients really benefit if they take a variety of approaches to treatment. That can include relaxation strategies, psycho education, cognitive, behavioral therapy, problem solving therapy, and acceptance and commitment therapy. So if you're wondering what the heck some of those are CBT or cognitive behavioral theory. That identifies and equips patients with skills to overcome maladaptive thoughts and patterns. It encourages emotional readjustment.

So both psycho education and CBT have been demonstrated to be effective in improving depressive symptoms and quality of life. Then acceptance and commitment therapy or ACT, it teaches patients how to tolerate difficult thoughts without being overwhelmed or dominated by them. Then it helps develop psychological flexibility. ACT has also been demonstrated to be equivalent in CBT in terms of its effect on mood and quality of life as well.

So the great news again is that depression is treatable. We just need to be persistent in making sure or that we're talking to our healthcare providers about the fact that we're having any of these symptoms. There still unfortunately is a really large stigma about having depression. I think that's one of the ... We talked about silver linings earlier. That's a silver lining of the pandemic. I think you got people to open up and talk more about the fact that mental health is a concern for many of us.

So you can also treat depression with medications as either in addition to or in substitute to some of the therapies I was talking about. But any combination of therapy and meds can be effective. Again, it's up to your healthcare provider to decide what's best for you. Sometimes medications though aren't a good fit for you because they could counteract any of your cancer treatment medications. It's very normal to seek treatments, including medications for mental health during cancer, during caregiving and other periods of distress. So make sure that you're talking to your healthcare team again. But there's different types of medication that can be antidepressants, that can be used.

Your doctor is going to decide what fits best for you based on your specific needs, any potential side effects it might have. They'll look at other medications that you're taking. They'll look at your medical history. The selective serotonin reuptake inhibitors or SSRIs, those are generally first line for treatment of depression and cancer patients. That's mainly because they're more tolerable. Some people can take up to two weeks to start feeling any effect or feeling a difference from your antidepressant medication. But generally it can take six to eight weeks for medications to feel their full effect. So in other words, give it time to work. If it's not working for you though, that needs to be communicated back to your healthcare team.

Some medication is particularly effective for improving moods and physical symptoms associated with major depressive disorders. So some times adding psychological treatment to medications might be helpful for managing those negative thoughts, and low self-esteem, and finding better coping strategies.

We're going to move on to talking about grief and cancer. I really love this quote on the next screen, "We shake with joy, we shake with grief. What a time they have, these two housed as they are in the same body." So we have the same physical manifestations to grief as we do to joy, which can lead to some feelings of confusion.

There are a lot of different types of grief. So one form of grief is called living loss. This represents how we may experience chronic or ongoing sorrow. It's that space between what is and what should have been. So this is where you might capture how you thought you'd be spending the rest of your life at this point in time, compared to in reality, how you are going to be spending it due to cancer and its after effects. So that could be as a young adult, my husband and I found out that fertility was going to be a huge barrier for us in our early marriage. So that was definitely a living loss for us.

Another form of grief is called ambiguous loss. So this is a type of grief that involves a sense of loss that's maybe unclear and defies resolution. You just have that gut feeling that there's some sort of loss, but not really able to describe exactly what it is. So it can make things much more complicated. Cancer also results in what's called loss of the assumptive world. So this is typically when growing up, we develop a sense of the world and have assumptions about if we lead a good life, that'll mean that there's good things for us. We work hard, we're a good person. We'll have a good life.

So these sorts of beliefs can form in our core. They can lead to beliefs about ourselves and what we expect to happen in our lives. But when we face illness or struggle, these beliefs can really be challenging and can feel disorienting. We might even feel stuck trying to make sense of this grief and work through it.

As I'm talking about these different types of grief, grief can happen at any point. It can happen when the diagnosis occurs, if there's progression of the cancer, if there's metastasis. Then of course, once we have grief when somebody has died from their cancer. But another type of grief is called disenfranchised grief. So that's when our grief is invalidated or minimized, or even just not publicly acknowledged. We might feel a sense of loss that's not recognized by people around us.

For instance, when people say you should just be happy that you're alive rather than expressing or understanding why someone might be sad that their cancer treatment has pushed them into menopause. It might have prevented them from having children, or it just leads you to not feeling good and feeling crummy all day. So this type of invalidation over what is considered appropriate or an inappropriate sense of loss, it can come from significant others, friends, healthcare professionals even.

But in general, it might be something that we internalize and try to take away from allowing ourselves to feel grief.

There's also complicated grief. Losing a loved one, it is one of the most distressing and unfortunately common experiences people face. Most people who experience normal grief and bereavement have a period of sorrow, of numbness, guilt, anger even. Gradually these feelings start ease. They can still be a bit debilitating, but they're easier to cope with over time. But it's when it becomes debilitating, and there's no improvement that it becomes known as complicated grief. Sometimes it's called persistent complex bereavement disorder. But in complicated grief, the painful emotions are just so long lasting and severe that you have trouble recovering from the loss and resuming your own life. So complicated grief is like being in an ongoing heightened sense of mourning that just keeps you from healing.

Then finally, we have anticipatory grief. So if you have a loved one with an advanced cancer diagnosis, you might already be preparing yourself for their end of life. So that's one example. Then as your loved one's illness progresses, you may feel like you've already lost them as a person. Sometimes a person feels like they've lost themselves even because they lose a lot of independence and become a different person.

So anticipatory grief, it shares a lot of commonalities with conventional grief, but sometimes can have unique factors too. It can be mixed in with hope that your loved one will live longer or survive their illness, while conventional grief signals that a loss has already occurred. So the National Cancer Institute defines the most common symptoms of anticipatory grief as depression, heightened concern for the ill person. It's that heightened concern that sometimes prevents a caregiver from taking care of themself, rehearsal through your loved one's end of life, attempts to adjust consequences of the loved one's life, anxiety, worry, irritability, and then just mourning changes in your loved one's personality or physical appearance can happen.

So with everything I just mentioned, how complicating grief can get, it's really difficult and really just unrealistic to expect somebody to be positive all the time. But that's not the same as not being hopeful. So hope is not wishful thinking. Hope is just adjusting and adapting over time. Some people early in their diagnosis have hope that they will adhere well the treatment. They have hope that there'll be a cure. They have a hope that surgery will get rid of all the cancer. I will say just as equally, when somebody is nearing end of life, making a decision about hospice, for instance, that hope just changes. Hope is maybe no longer for a cure. Hope is for a comfortable death. It's for a good quality of life with the time that you have left. So again, hope is not to be confused with being overly positive,

I'm going to give you some time to reflect again. I'm just being conscious of our time. So we won't take up too much time doing this one. But what are you grieving? Again, a grief can be a situation. It can be that hair loss. It can be fertility. It can be that you can't drive, and you used to be able to. But your medication doesn't allow it. Perhaps on top of all of this, you are grieving the death of somebody in your life as well. So just take some time. Think about what you're grieving, but also think about how you can honor and acknowledge your grief. I'll give you a few minutes to think on that. So what are you grieving and how can you honor and acknowledge your grief?

We're going to transition here from grief to resilience. I really believe that instead of focusing on being positive in the face of cancer, it's really resiliency that we need to focus on. So I'm going to let you read this quote on the screen for yourself this time, but there are many ways to define resilience. It can range from bouncing back from adversity to positive adaptation or growth when there's a disruption in life. Most people will agree though that resilience is a process. It's not something you have automatically, but it's a process that begins after significant life difficulty. It really involves a lot of ongoing collaboration.

So there's a model of resilience that recognizes the way in which individuals experience the world before cancer affects their response and ability to cope with cancer. So in this model, mindfulness is the foundation of resilience because mindfulness allows you to remain present in whatever challenges life presents. I just want to point out again in that quote, it reiterates the fact that resiliency is a process that happens over time. So there's that word again, it's an active process of facing adversity related to your cancer experience. It's not something you either have or you don't have. It's something that you work to achieve.

Resiliency is the ability to restore emotional and physical functioning when confronting with stressful events. It involves behaviors, thoughts, and actions that can be learned and developed in anyone. A lot of times we can cultivate resiliency through mindfulness. So this can help. Mindfulness can help us with a wide range of physical and psychosocial outcomes that include anxiety, depression, stress, fear of recurrence, fatigue, chronic pain, difficulty sleeping, and immune function. Mindfulness has also been related to increases in perceptions of social support, optimism, and overall quality of life. So again, it's a skill that can be learned.

So in this reflection, I'm going to actually walk you through a brief guided mindfulness practice. So just take a moment, find yourself a position that's comfortable. If you feel like it, go ahead and close your eyes, or maybe just a soft gaze down at the floor, away from your computer screen. Take a few easy, slow breaths. With each, trying to release any tension you might notice in your body. Just simply begin to notice your breaths, feeling your stomach rise as you breathe in, lower as you breathe out, notice the rhythm of your breath. It's only natural that your mind might begin to wander. But as it does, gently remind yourself to return your focus on your breath. Stay in this moment, gently breathing, connecting with your own breath, allow yourself to feel whatever you're feeling, and be present with your current experience.

So in addition to mindfulness meditation, there's three different actions that you can take daily that will help you with mindfulness. One is to look for the good. The second is to spend 10 minutes in mindful thought or reflection. The third is to do an act of kindness. So one final poll question for the day, Amy. I want you at all to just think about which of these three is something that you think that you can work on over the next month. There might be multiple, but just pick one. Which do you think you could focus on over the next month? A lot of quick answers coming in.

I know some of you haven't had a chance to fill it out yet. But, Amy, let's go ahead and share the results. So there's a really good mix, looking for the good, 10 mindful minutes and acts of kindness that we're thinking about and moving forward with. I just have a few more slides, and then we'll have time for our questions. Our key takeaways, distress and depression are treatable. You just have to be open to bringing those to your healthcare key's attention. Resilience can be learned and strengthened. Positive thinking is not the goal. Acknowledging grief is really important. You don't have to do this alone.

So again, Cancer Support Community. We have some resources for you. We are in several places across the country. We have our help line 888-795-9355. This has both evening and weekend hours for you. We have our Frankly Speaking About Cancer Educational Series. We talked about Cancer Experience Registry, which is where a lot of the data I shared came from. We also have Open to Options, which is a research proven program that is helpful if you have a fork in the road and are trying to make a treatment decision. We don't tell you what to do, but we give you guidance on formulating a good list of questions to go back to your doctor so you can make an informed decision. We are onto our questions. I'm going to stop my screen share.

Melissa Rosen:

I'm going to unmute myself, Kelly, thank you so much. That is so much to think about. We had some amazing questions come in prior and some equally important questions come in during, I'm going to try and combine them. We don't have a lot of time. To try and hit the ones that you didn't touch upon. But somebody asked, and it was also a question I had. One of the slides mentioned something called Unrecognized Distress. Somebody asked also, is there something called subconscious stress? How do you know if you're stressed or distressed when you don't have have those symptoms or do you need those symptoms to have that?

Kelly Hendershot :

You don't necessarily need those symptoms to have it. It's when you have those symptoms for a persistent period of time that triggers you to know to go to a medical professional, to seek advanced help. But I definitely think there is some unconscious or subconscious distress that comes into play. That's why it's important. If your doctor or healthcare team has some sort of distress screening questionnaire, sometimes it will bring to light some things that were buried under the surface for you and make you more aware that that is something that's impacting you.

Melissa Rosen:

Thank you, thank you. I see there are a couple of hands raised. We're not going to be unmuting anybody. So if you have a question, please put it in the chat so we can try and get it answered. Thank you. How's this for another one? Somebody says, I'm going to put a couple together. These were from caregivers. So somebody said, "I have no time for grief. I need to be strong for my loved one." Another person said, "How can I show empathy without feeling condescending? Every time I do, my loved one says, I don't understand. You don't understand what I'm going through." So how, from a caregiver's perspective, should we be thinking about that?

Kelly Hendershot :

Yeah. So I think grief is something you have to make time for. If you are pushing it under the rug, you are only complicating things for yourself and actually for your loved one. There can be a lot of subconscious responses to not exploring that grief in our lives. It doesn't mean if you're the caregiver, that you may be talking about death, mortality, things like that with the person who has the diagnosis.

But find yourself a support group, find yourself some friends, a good community who really understands what you're going through. My husband and I religiously attended support groups. He was in one room for people with cancer. I was another for caregivers. I have no idea what he talked about. He doesn't know what I talked about, but we both got our needs met. So there are lots of communities like that out there. The second part was about empathy, how to be empathetic?

Melissa Rosen:

Yeah. Every time I try and offer support, I'm told that I don't understand what's happening. I couldn't possibly understand it.

Kelly Hendershot :

I think that's where being empathetic versus sympathetic is really key because there's no way as a caregiver we're going to understand exactly what our loved one is going through. But it's asking the person with the diagnosis to share how they're feeling, to be vulnerable and tell you what they're going through. Acknowledging that sometimes no, you're not going to get it, but be supportive if your loved one wants to be in a cancer support group where they can be around other people who are diagnosed and get that support as well.

Melissa Rosen:

That's great. Thank you very much. A couple of other questions have come in. So just a very quick magic bullet answer. When somebody tells me I need to be positive, I need to stay positive. It's so important to stay positive.

Kelly Hendershot :

Yeah. It it's going to depend on the person, your relationship, how you might respond to that. But I think sometimes it's just being vulnerable and saying, "It's more important to me right now that I'm real about my feelings and express my emotions than I'd be positive all the time." Because I think people, they want us to be positive for their benefit. We need to focus on ourselves, especially if you're the person with the diagnosis.

So sometimes it might be turning away from a friendship or taking a short break so that you can focus on yourself. You're not there to be somebody else's cheerleader. You're there to get through the diagnosis go through treatments, get your own support that you need. It's not your responsibility to be the cheerleader for everybody around you.

Melissa Rosen:

Great advice. One of the presentations that Sharsheret does, we say, we hope that everybody has a friend or someone in their life that they can talk to honestly. But don't use a friend that does something else for you, that is willing to cook, but can't hear what's going on in your mind or is willing to give rides or things like that. Use the friend that is open to hearing your true emotions and understand that it's a burden for someone who can't take that in.

Kelly Hendershot :

I unfortunately did see something pop up in the chat that I need to address. Somebody said that their support group shies away from these heavy conversations. That's really in unfortunate. If your support group is led by a licensed mental health professional, a psychologist, social worker, counselor, talk to the facilitator. That is something that they should be recognizing and make sure that they feel comfortable having those heavy conversations. We have to be real in what's going on around us. It changes day to day.

Melissa Rosen:

That's a very important question. Thank you for addressing it. Somebody asked a different type of question, which is do the treatments themselves, the chemotherapy, the hormones, whatever it is, does that impact our state of mind from like a biological perspective? What can we do to counter that?

Kelly Hendershot :

Absolutely. If you're noticing that you're having a lot of negative side effects, talk to your healthcare team. Because they might be able to tweak your medications, it might just be something that your family needs to learn to live with. For example, 3:00 PM every day, that's when my husband's prednisone kicked in. Not being on it would've killed him sooner. So I just tried to be a little absent at 3:00 PM when I knew that he was going to be crabby because of his treatment. But absolutely, there could be something in your treatment that is causing depression and anxiety. So it's important to talk to your healthcare team about any symptoms that are really being detrimental to your quality of life.

Melissa Rosen:

Good reminder. When people say, "It's just in your mind." No, it actually isn't just in your mind. Okay. So a couple more, let's try for one more question. Then maybe with some of the others, we'll get you to write a blog for us or something like that.

Kelly Hendershot :

Sure.

Melissa Rosen:

So there were several questions about people dealing with advanced or metastatic disease, knowing that they've run out of treatment options, feeling like they have nothing left to give to themselves or the family around them. So what can they do with that grief, which is so warranted? How can they make this time of their life as strong and happy or meaningful as possible?

Kelly Hendershot :

Yeah. I think that is first connection of all, identifying what quality of life looks like for you. Because once you have a list of things that mean quality of life in your mind, you're going to have some things that you can focus on. You can let people know that instead of a treatment possibly, you are focusing on doing X, Y, and Z, because it brings you joy. You want to be able to spend time with your friends and family.

So I do think it stems from knowing what quality of life looks like for you and trying to engage your loved ones in conversations about what that means, asking them what quality of life means for them as well. Don't make it a dialogue. Or a monologue. I'm sorry. Make it a dialogue between two people. A lot of times, we're afraid to hear what somebody else is thinking. So if we're sharing in that vulnerability, it can make those conversations a little bit easier.

Melissa Rosen:

Thank you. I think that's incredibly helpful advice. I want to thank you. I wish we had time for more questions. We do get a ton of questions about COVID. So I just want to point out that many organizations like Sharsheret, like Cancer Support Community or Gilda's Club have stepped up their types of support and their levels of support. Because whether one is facing cancer or not, COVID has definitely made life difficult, both physically and from an emotional or psychosocial perspective for all of us. So we'll try and get some more information to you about that as well.

But now, I want to thank Kelly for sharing her both professional expertise and personal experiences. I actually found your presentation very hopeful. I hope you guys did as well. Once again, thank you to Cancer Support Community for partnering on this important webinar. Thank you to ASI, GSK, Merck, CGEN, the Siegmund and Edith Blumenthal Memorial Fund.

Our evaluation survey has been posted in the chat box several times. You can even click it now and fill it out as you listen to the last few moments of it. It's really important to us. We use those to create new content and programs, so we'd be very grateful for that. Reminder that Sharsheret is here for you and your loved ones during this time. We provide emotional support, mental health counseling, and other programs, all designed to help you navigate the cancer experience. They're all free, confidential, and one on one. Our email address is in the chat box. You can reach us by just emailing us at Clinicalstaff@Sharsheret.org because our social workers are available to each of you. You are our priority, your health, your wellbeing. We're going to get through this together.

Finally, I wanted to let you know that if the idea of resiliency really resonated with you and you want to hear more, we have an amazing program next week with Dr. Edith Eger. It is part of our book club, but you most certainly do not have to have read the book ahead of time. She is a psychologist who is also a Holocaust survivor and has spoken significantly about resiliency for a variety, not just Holocaust, but for illness, for lots of things, about resiliency in life.

Then if you're looking for another way to reduce stress, just a couple of days later, we have a combination of our Sharsheret in the Kitchen Program and our Shalom Shabbat Program. We're going to do a chala making presentation because chala making actually can be very meditative. That's a way to reduce stress and anxiety. Those links are in our chat box. We will do our best to answer all the questions that did not yet get answered. I want to thank you for joining us today. Again, thank you, Kelly. We look forward to connecting with you on another webinar. Thank you very much.