

Survivor's Guilt, Trauma, and Life Beyond

With Dr. Katie Salyer

National Webinar Transcript

December 4, 2023

Presented by:



In Partnership with:



This program was made possible with support by:



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

Aimee Sax:

Welcome and thank you so much for joining us for tonight's webinar during this difficult time. I want to begin by saying that Sharsheret stands with Israel. We mourn with the families and friends of those killed, pray for those injured and kidnapped, and hope for lasting peace. As our hearts are focused on Israel, Sharsheret continues to provide vital cancer support and education to thousands who depend on us.

We're glad that you're here tonight for survivor's guilt, trauma and life beyond. I'm Aimee Sax, Sharsheret's California Support Program Manager. For those of you who don't know about Sharsheret, we help women and families facing breast and ovarian cancer, as well as those who are at elevated genetic risk through free, confidential and personalized support and resources. And we also provide health education throughout the country. One of our goals is to make sure that we are offering helpful information and giving you the support that you need in addition to our vital services that can be found on our website or by emailing us. You can access prior webinars on a range of cancer related topics as well as access our calendar of upcoming virtual programs through our website.

Before we begin, a few housekeeping items. Today's webinar is being recorded. Participants faces and names will not be in the recording as long as you remain muted. It will be emailed to registrants and posted on our website along with a transcript in the next week or so. If you would like to remain private, you can turn off your video and rename yourself or you can call into the webinar.

Instructions are in the chat box now for both of those options. You may have noticed that all participants were muted upon entry. Please keep yourself on mute throughout the call. If you have any questions for our speaker, put them in the chat box either publicly or click on Sharsheret in the chat box to submit a private question and I will ask them throughout the program.

We want to thank our webinar sponsors, Daiichi-Sankyo, GSK and the Cooperative Agreement DP 19-1906 from the Centers for Disease Control and Prevention. It is because of their generous support that we can offer webinars like this one. And a very special thank you to our program partner Cancer Wellness Center. We are so lucky to partner with them. They provide lots of support to the cancer community and we'll hear more about that in just a minute.

Almost all of our Sharsheret callers speak about survivor's guilt in one way or another and or another. This topic comes up in many ways, whether it's someone who was diagnosed with an early-stage cancer and they tell us they shouldn't complain because they know it could be worse. Maybe they know or have known people who have a more advanced cancer diagnosis or a more advanced treatment plan. Or maybe it's even someone with stage IV cancer who feels like they can't complain about treatment because they know people who treatment has stopped working for. We're not here tonight to say go ahead and complain, but we're not *not* here to say that. What I mean is survivor's guilt tells us to minimize our feelings. But the evidence shows that minimizing feelings prevents us from processing our feelings.

And we know that emotional health and physical health are connected. So it's really important not to sweep feelings under the rug so you don't trip over that rug for the rest of your life.

What connects everyone from stage 0 to stage IV is the fact that your doctor said the words, "you have cancer," and in that moment, you were all united in the fear of what comes next.

You didn't know how your story would go and you all worried about how it could end. That is powerful and important. Your feelings are powerful and important, and worthy of talking through. You are worth the support that we're here to give. One way Sharsheret can provide that support is through our team of social workers and our genetic counselor.

Another way is our free survivorship kit. It's so customizable that people find it useful, whether they order it the day they're diagnosed or years later. And it's tailored to your needs whether you're diagnosed with stage 0 or stage IV and anywhere between. To order your kit, you can click the link in the chat.

Now I'd like to introduce Savina Chacheva, Program Director of our program partner, Cancer Wellness Center, so she can share how they can also provide support to you and the cancer community. Their information is in the chat now. Thank you, Savina.

04:14:17

Savina Chacheva

Thank you so much, Aimee and Sharsheret for partnering with us on this great program. The Cancer Wellness Center is a nonprofit organization with the mission to improve the physical and emotional well-being of anyone impacted with cancer. And we do so all free of charge, regardless of insurance income level and legal status.

We offer education programs, wellness classes and support services, which include counseling and groups for those diagnosed with cancer, their caregivers, and anyone who's lost a loved one to cancer. Our services are both in-person in Northbrook, Illinois, and virtually on Zoom. Many of them are also delivered in Spanish. If you would like to learn more about the Cancer Wellness Center and connect to our free products and services, please visit cancerwellness.org. All of that is in the link is included in the chat. Or you can contact me directly with my email in the chat as well. Thank you.

05:06:03

Aimee Sax

Thank you so much Savina, for this and for all you do. We're just so lucky to partner with Cancer Wellness Center, and not only for all you do, but also for introducing us to this evening's speaker.

I'm so excited to introduce Dr. Katie Salyer. Dr. Salyer obtained her Doctorate of Clinical Psychology from the Illinois School of Professional Psychology, specializing in health and stress psychology. Dr. Salyer most enjoys providing support for the sector psycho physiological effects of illness, caregiving, grief, stress, burnout and trauma. Dr. Salyer has served children and adults in hospitals, rehabilitation units, medical offices, nonprofit agencies and outpatient practices for more than 20 years. Take it away, Dr. Salyer.

05:53:15

Dr. Katie Salyer

Thank you so much. I appreciate the introduction and the opportunity to be here today and to present this important topic with everyone today. I'm going to go ahead and share my screen and get us ready to go here. All right. So we're going to go ahead and get started. But first, I

would like to reiterate that as a psychologist who specializes in health psychology and trauma, it's a really, really important request I have.

This is a heavy topic. This is really hard to talk about. It can be really tough stuff. And so I really want to encourage folks who are listening in today to take good care of themselves, to listen closely to how you're doing throughout the presentation. I want to remind you that this is being recorded. And so if along the way you come to find that the topic, the things which we're discussing are just feeling a little bit too overwhelming, I really want to encourage you to take a break.

It's okay to come back to this at another time to watch this video later. Ultimately, it's important and you'll learn throughout our conversation today about the importance of listening to your body and really just going at its own pace and taking in this information with care. So I once again want to thank Sharsheret and the Cancer Wellness Center for bringing me in today so we can talk about survivor guilt, trauma and life beyond.

So to begin with, we're just going to define survivor guilt. The term is pretty straightforward. And my guess is if you're here, you probably have a pretty good idea of what we're going to discuss today. But the definition is specifically the guilt that happens when someone survives a situation physically and or psychologically, while others who seem equally deserving do not. We're going to talk again in a moment about some specific words that you'll find in this definition, particularly that situation described as both physically and or psychologically. But we'll go ahead and begin with kind of identifying some ways that survivor guilt can show up what might look like. Survivors oftentimes report feeling unworthy. I think Aimee did a wonderful job at the start of this presentation, really listing out any number of different possible ways that individuals can feel either diagnosed at an early stage and especially lucky. Other individuals who may have more advanced diagnosis may still feel that survivor guilt, having known the chemo buddy in the chair next to them that didn't fare as well. There can be a lot of heavy, deep feelings about just whether or not somebody feels deserving of their health, whatever state that might be in, as it compares to others that they've known and seen along the way.

Survivor guilt can show up as a really hard time taking in those celebratory feelings. So whenever you reach a milestone for some individuals as they exit treatment, they ring a bell. Those celebrations often are surprisingly mixed in their feelings. There can be a lot of guilt, heavy feelings of sadness and grief. So that can really complicate that transition for individuals not fully understanding what it is they're doing.

It's the time where you should be celebrating, and yet they feel this heavy sense of guilt and grief. Some individuals, as we described in this definition, may instead feel survivor guilt as it relates to the psychological collateral damage that may come from a diagnosis and treatment. So moving through the journey of cancer is tough and it reaches every nook and cranny of life. So it can impact relationships, families, it can relationship communities, faith communities or faith itself. It can impact job security and financial security for individuals. And it certainly has a lot of there are a lot of close calls when it comes to having access to treatment. That's a very important, very basic level of getting needs met. And if you move through a hospital system, if you've gone through waiting rooms, if you have gone any length of time dealing with cancer in your life, chances are you recognize that it does not hit equal.

They hit people equally in this kind of psychological way. And so individuals can really struggle knowing that maybe they come out on the other side, having maintained that job and financial security, whereas somebody else has not. In other cases, it can be knowing that their family came closer together with the diagnosis, whereas another one ended in a divorce or another rift.

So these kinds of comparisons often can result in that feeling of guilt and grief, that fear of not being worthy or deserving of that outcome that they've experienced. In many ways, survivor guilt can look unexpectedly deep, or it can be masked by these heavy duty feelings of existential dread. So for individuals who have moved through their diagnosis and treatment, or have reached a certain point in time and continue to live with cancer or live beyond that diagnosis and treatment, there can come a point where it feels very existentially challenging. You know, it's hard for individuals to know how to make meaning of their survivorship, what they can do with a new lease on life or a second chance, so to speak, what they're supposed to do in their future. That word survivor. I mean, we could have a whole other webinar just on that word alone and just reconciling that identity, what it means to be a survivor who qualifies as being a survivor.

11:48

Dr. Katie Salyer

That's different. Whether we're talking about the National Cancer Institute diagnosis of survivor guilt that can instead say, maybe I'm not deserving of that title somewhere, or somehow some survivor guilt can show up instead as feeling a heavy sense of responsibility so individuals can feel like it's their job, their duty. Once again, that feedback is essential kind of purpose that they hold to bring other screening to their family members in for additional genetic testing, for example, to find support for others, or to be that support for other individuals who are moving through that diagnosis or treatment.

And it's also a possibility that in some cases, cancer patients and survivors in the midst of treatment or beyond can have an opportunity to experience that guilt more about how they've disrupted their loved one's lives. There can be a sense of feeling like a burden. There can be a clarity in knowing that their family has had a disruption in their world due to this cancer experience, the diagnosis, treatment, even the emotional effects in that way.

So cancer survivors, particularly certainly providers as well, can encounter some of these experiences. And while we won't focus on it today, I wanted to at least bring your attention to the fact that caregivers, friends and family also can experience survivor guilt. I raise this as attention today, in part because many individuals occupy both of these categories. So cancer, traveling and families, you may both be a survivor, a provider, and also be caring for someone, loving for someone, loving someone who's moving through a diagnosis.

So survivor guilt and individuals caring for a loved one is most evident and apparent when we're talking about a loss. It can be very hard to lose a loved one to cancer, and there can be worries about not having done enough or said enough. In other cases, caregivers and loved ones can really struggle with survivor guilt while supporting a loved one moving through cancer.

They may feel like their needs are small potatoes and now don't measure up to this individual in their loved one who is moving through such an important, heavy, hard part of life this this big

hardship of cancer. And so it can really impact relationships because it may alter what they communicate or disclose or how they may or may not engage with an individual. Sometimes they actually grow more distant not knowing how to support. So our focus today is really primarily on the individuals diagnosed with cancer and surviving cancer. But it's also important to be aware of that impact in the community as well. So we're going to move on and talk about the recipe for survivor guilt. This is not a formal recipe or formal set of ingredients. It's a number of things that come to my attention and that we recognize being part of what creates the environment and predisposes individuals for experiencing that survivor guilt. Certainly that very first and most important ingredient is going to be that perceived threat or danger. And I remind you, this may be a physical practice. It may be a psychological threat. So this can relate as much for the cancer diagnosis itself and the physical impact of health or mortality. And it may also once again be about relationships, financial security or otherwise. The two ingredients listed are lack of control and justice oriented values. They really point to the fact that a lot of survivor guilt can come from situations that don't always follow rules. It's not always clear that one individual's efforts will result in one outcome and another individual. Smaller efforts can sometimes result in a different outcome. So there's not always full control or ability to anticipate those outcomes. It's hard because at the end of the day, survivor guilt comes in part because there aren't true rules and hard guidelines about how things come to be as they are. So it doesn't always make sense why this person survived and that one did not or this person was caught early and that one was not, or how this individual had the genetic testing done and now is fortunate enough to have that heads up, whereas maybe a family member did not. Survivor guilt is also impacting on those meaningful relationships. In other cases, it can just be a value placed on humanity. That's an important predisposition for survivor guilt. Individuals who might feel or think deeply if you've ever heard those terms, highly sensitive people, empaths or just sensitive folks may be more inclined to have those deeper feelings of survivor guilt and grief in that regard. And it's important to notice as well, and you'll hear us talk more in this conversation about trauma. So a past history of trauma or someone who might be encountering this cancer experience with that ongoing trauma reaction is going to be more likely to experience that survivor guilt. While we've identified some individual predispositions toward a survivor guilt experience. I want to take an opportunity to also identify the importance of language. So this is really pointing to our cultural and societal values and the way that we communicate that in our words and how that can really directly impact individuals in how they see themselves as a survivor or move their way through a cancer diagnosis and treatment. So I'll bring your attention to the word survivor itself. Right. We said earlier that it's a heavy word, it's meaningful. And before calling individuals survivors, there was a common use of the word victim. So that certainly doesn't feel too good. In other cases, people don't know whether or not they feel like a survivor, but then calling themselves a patient doesn't quite identify it. So you can recognize here how there is a power in what word is used as an identity. And individuals may feel more or less deserving of that word. Sometimes you'll even hear folks say a cancer warrior. In that regard, folks will often describe cancer and the battle with cancer as having been won or lost. This really directly links to those justice-oriented values and highlights

the fact that it's not always the outcome is not always based in a clear set of rules or expectations.

You can fight as hard as you can fight and still not always win the battle. And so that disconnect between the effort and the outcome can really cause a lot of confusion, grief, guilt. And then we also want to talk about that word, the "gift" of cancer. And I certainly want to support individuals who find meaning out of these choices and language, these words used.

They can be very transformative and supportive in how that diagnosis is made sense of. But when we use some of these different words like that gift of cancer, it can really add a certain weight or heaviness. It might also suggest to an individual that there is that need for some transformative or existential growth that comes from this experience.

And in truth, cancer can sometimes just stink, and it doesn't always have to have a magical outcome. You'll also notice and again, this could be another opportunity for quite the discussion, but a lot of the language that we're talking about here is really there, the niceties that you hear. So you'll often get that sprinkled in with things like you're only given what you can handle or there's got to be a reason for this.

And so the words we hear or give others when moving through a diagnosis can really be powerful. In many cases, the intentions are good, and for some folks they can really be wonderfully supportive and in other cases it can really add to that sense of survivor guilt, the fear that you may not be deserving or worthy of these kinds of niceties, confusion over Am I really brave if I didn't want to do this in the first place, I didn't ask for it.

20:23:03

Dr. Katie Salyer

And just some of that existential kind of transformative language around that gift. So it's important for us to just be aware that this is a lot of the air we're breathing, the water we're swimming in is that messaging around cancer and what it means to have that diagnosis.

So this is a tough statistic to read, and it's one of the few slides I will read out loud: in a national study conducted by the Lung Cancer Alliance in 2019, 55-64% of people surviving lung cancer are found to experience survivor guilt. I think this slide is pretty solidly done in silence. I don't know that there are too many more words to add except to normalize that survivor guilt is, in fact, according to this very study, it is something that the majority of individuals experience.

So I want to really take an opportunity to set that stage and to continue sending that message of normalizing survivor guilt. We're going to shift gears next. We're going to talk about trauma, the definition of trauma for the purpose of this presentation, because once again, there could be any number of additional webinars beyond this one. I could definitely get moving on that word trauma and kind of explaining what that might be.

But for today's purposes, we're really going to focus on what trauma is in terms of being a normal response to an extreme stress. It impacts brain, body, spirit, and once again, every nook and cranny of life. So you might ask how trauma is included in a webinar related to survivor guilt. Well, let's take a look at the recipe.

Might look a little familiar. So trauma is inherently a result of a perceived threat and danger, something that's seen as being larger than life, bigger than what can be handled. Once again, you see those terms lack of control, justice oriented values. Trauma oftentimes defies any

sense of responsibility or any sense of control. Rather, there's there's no justification for what may happen.

It's beyond that sense of understanding, comprehending the why or having much control over how it comes to be. The recipe for trauma certainly has a lot to do with relationships, and trauma is much more likely. Or PTSD, rather, as a formal diagnosis, is much, much more likely to be a result when an individual does not have an adequate connection or support.

It's amazing. In other studies we've identified how the there's the power of just one solid, regulated adult in a child's life can be extremely resiliency building and protective in terms of PTSD. So, you know, lack of connection is a very closely intertwined piece of that trauma experience. And once again, we talk about deep thinkers, deep feelers, folks with past traumas or histories, all of these things make someone a bit more predisposed and likely to experience trauma.

This is going to be another one of those slides where I'll read aloud that up to 90% of people diagnosed with PTSD and having survived an event in which others died are reported as experiencing survivor guilt. In a 2018 UK study. It's another one of those very heavy kinds of statistics to encounter. So what we can identify here is that having survivor guilt does not necessarily mean you have trauma.

Having trauma doesn't automatically mean you have survivor guilt, though it's much more likely. But my hope is today that we can really build a better understanding of survivor guilt and trauma as being relatively common and even normal responses to a diagnosis of cancer, the treatments and all of what comes thereafter. So we're going to come to better understand trauma, and I'm going to do my best to keep to the highlights of what we can use in this webinar as far as coming to understand the basics of trauma.

So once again, we want to really normalize that trauma is really just the extreme end of a more normal stress response. In actuality, a traumatic reaction, so to speak, is a very adaptive protective reaction that all of our brains, bodies are designed to do. It's a very, very complicated sometimes, but ultimately our brains and bodies are designed to enact these different mechanisms these protective reactions, and to keep us safe. It's ultimately a result of when we, in an instance, completely unconsciously, when our brains and bodies identify that we have exceeded our window of tolerance. What that really means is that we've identified that the threat coming our way is more than we can handle physically or psychologically. It's that proverbial grizzly bear.

It's coming to eat me. I cannot outrun it. I cannot fight it. And so there's this reaction that happens very automatically in our brains. And bodies get hijacked and certain mechanisms take over. For that reason, the field has really started to talk about PTSD, which is really just that sort of arbitrary official clinical diagnosis. PTSD is really recognized in some cases more as an injury than a disease.

The reason is because our brains really change when we encounter a traumatic response, when our stress response really takes over, our bodies change. For that matter, memories are stored differently. The body remembers if you if you've maybe heard that statement and it's also an important consideration to consider that trauma can come in an acute form, meaning an acute incident that might be.

I can guarantee that anyone watching this webinar is probably going to recall the day that they got the news of their diagnosis, maybe can remember the tone of voice in the doctor, what

they were wearing or other sounds or smells, even though that sort of acute moment in time is itself its own trauma. Complex trauma, though, is also possible.

And what complex or chronic trauma might this describe is really more of that prolonged amount of time. So cancer certainly can qualify for this as well. If you go through a length of time for treatment or are persistently in maintenance treatment, for example, that level of stress continues to sustain itself quite high. And it means that brains and bodies have needed to adapt for a long period of time to make sense of the world around them, to stay safe, to be protecting and to make sense of it.

So trauma has a lot of information that can be really helpful. If you have any thoughts about possibly wanting more support or wondering whether or not you may or may not have that traumatic response or true PTSD occurring, it's also, in many cases, misunderstood in the world. So most people will recognize that term fight or flight, but in the trauma world, we actually understand it's a much more complicated relationship. You'll see it on this slide, actually. It lists fight or flight. Freeze is actually a very common and recognizable experience in trauma for cancer patients. But there can also be finding fixed flaps, all kinds of different presentations. And so it can be easy to sometimes overlook trauma because it's not what you might expect it to look like.

So this is an opportunity for me to help you identify when you are in a bit of trouble territory, when you might be in the position of recognizing that this trauma reaction is impacting or might need some additional support. The very definition of PTSD requires, technically speaking, these two arbitrary symptoms to be met in order to have the diagnosis.

We don't really have to get connected with diagnoses, though. I want you still to be able to use the information you get today for yourself. But true PTSD or a trauma response means that you have an impact upon responsibilities, relationships in life persisting beyond six months. So meaning six months after the trauma having occurred, you're still encountering symptoms of trauma and stress response.

This is a complicated definition. If we're talking about individuals who are persistently in treatment, you know, at what point do you consider yourself post-traumatic or, you know, after the incident, if you're in maintenance treatment for the rest of your life, or do we pick the date of diagnosis, do we pick the date of surgery, or do we put the date of finishing diagnosis or finishing treatment, rather?

So you can see how these definitions are just essentially inadequate to really, well express the very complicated experience of cancer. But I would want you to be noticing for yourself if you're encountering any of the symptoms that we have listed here, intrusive thoughts and preoccupation, maybe disrupting life or coming in unexpectedly. So there can be extreme, uncontrolled or unexplained moods.

30:20:13

Dr. Katie Salyer

Sometimes this can look a little bit like that fight response. You've had individuals who might really feel angry, really upset and relatively displaced, you know, maybe upsetting a relationship when in reality, you know, there may be that stress response that's happening there. In other

cases, there can be indecision, overwhelm, confusion. This is maybe an example of a freeze response.

So folks will often say that there's a point in which they feel numb or shocked. That's a really traditional explanation of that freeze response. And most anybody will move through that at some point in their diagnosis and treatment. Just that shock and numbness. Sometimes for individuals, though, that can persist for quite a length of time, they really struggle to get through that cog fog, that fuzziness that comes through and really stay focused again, avoiding or over engaging is another way that trauma can show up.

Avoiding can be just ultimately procrastinating and delaying, not wanting to make that appointment, you know, not wanting to, you know, ultimately just doing the best you can to avoid any reminder. I had individuals with any number of different examples where they didn't want to clean out a closet because it had camisoles that they used, you know, during their treatment to best use, you know, to best manage their drains.

And so there's that avoidance. They may know and want to do something, but their brain and body just really don't want to go there. Over engaging may be another sign. And this is actually an opportunity to point out sometimes trauma can look very positive. Some individuals will really powerhouse into a diagnosis and may move through it in such a way where their only identifiable reactive reaction and response is that of encouragement and positivity.

And this is going to be okay. And those are once again phenomenally supportive and great for individuals when it works. In other cases, there can come a point where that that need for absolute positivity can interfere with other very normal reactions grief, loss, sadness, anger. And so individuals who really have to have those blinders on and over engage or might in the instant that they're diagnosed and with no judgment to each their own.

But the the minute that they're diagnosed me may really occupy that space of identity may be walking the walks and, you know, wearing the pink or the teal or, you know, they're going to occupy that space much more enthusiastically. It helps them to cope through. But you can recognize once again, that's a protective reaction. That is an example of a stress response.

And moving through that high stress time, it can make sense for individuals to avoid or over engage. But if we continue seeing that move beyond treatment, those can be indications that somebody has that continued trauma reaction going on. It's unresolved in that way. And then the last symptom I want to bring everyone's attention to is certainly hopelessness, meaninglessness, despair.

These are those heavy, heavy words and feelings. Any time someone really is feeling like it's just hard to get up and out of bed or hard to make meaning of things or things, you know, it's just really in over their head. We all have our bad days, maybe our bad couple of days, but I really encourage you to reach out to someone.

If that goes on beyond a week or two, there's no need to necessarily struggle in that darkness for too long, and it can be an opportunity to really reach out, ask for support and help. So that is where we're going to turn the page here and talk a little bit about life beyond. So if we want to move from guilt and grief to growth, what's that going to look like?

So once again, this is going to be oversimplified. This is no official clinical kind of term, but trauma is very easily rooted in situations where there is a feeling of urgency. Trauma is very much about force. I have not yet met anyone who asked for a cancer diagnosis. It was against their will. The trauma is rooted in that feeling of pressure.

It's high stakes. There's this high demand. Things have to be done the right way and that really compounds with that sense of urgency. These high stakes and high stakes are not just high stakes, but they have to be acted upon immediately. Yesterday, if at all possible. Okay, I have this diagnosis. Why can't I do surgery right this minute?

And trauma is also, as we mentioned earlier, very common in situations where there is a feeling of disconnect that can be disconnect from relationships. Trauma oftentimes can result in a disconnect from your body, especially if we're talking about a medical trauma, really, that intersection of when chronic illness, that cancer diagnosis and treatment and all that it does to the body, then really disrupts the relationship we have with that body causes this real disconnect, almost like you know, from the neck up and neck down.

These are two different operating systems sometimes. So knowing what trauma is best rooted, kind of its most fertile ground, the environment in which it thrives best when I'm hoping to do today is to empower you to know how to create an environment where healing can be rooted instead. So this is a space in place where, you know, this is going to be practiced, may not be perfect, but practice is the key.

I would encourage you in any state of healing from your cancer diagnosis, whether we're talking about straightforward guilt, survivor guilt or trauma or an intersection or any number of things, processing and healing from this huge experience is going to serve you well if you can maintain these different factors. So compassion is a big one. Cancer is a big deal.

It's it's a big deal. And it can be a real rush sometimes to get over it, to move beyond it, to feel better, to go back to life, to get back to work sometimes, to get back to family, to get back to whatever might be the case. And that may be well intentioned. But ultimately, there really needs to be that place and space of compassion and validation where you can give yourself a break and remember that this, in fact, has been a big deal.

Maybe it continues to be a big deal for you as you continue to treatment. And so there's got to there's there's an importance in holding that space for self validation. Trauma work also incorporates a lot of consent. The other word that I'll use oftentimes in the work I do is permission. In some cases, that means giving yourself permission to be mad.

That means giving yourself permission to grieve. That gives means giving yourself permission to not make a gift out of cancer in some cases. Right. Like maybe you'll get there one day. But permission is really about sort of reversing the effects of that force and pressure that trauma puts in your world of life. This is going to be really key when it comes to pacing yourself.

Consent or permission is a big factor. When I talk with individuals about returning to a social life or returning to work or going out into the world again, giving yourself permission to talk about it when you want to, permission not to talk about it. When you don't want your permission to disclose or not disclose, but ultimately not feel like you have to put on the good face or altogether be put together for those social events can be a real help, especially as we talk about moving through the end of the year.

Social engagements, engagements, sometimes holidays, permission, to just, be in whatever state you might be in. This is one of my favorite ones. So creativity and curiosity. Interestingly, this is again oversimplified, but they're actually they use almost the exact opposite mechanisms and structures in the brain. So trauma will show up one way on a screen, in a scan or otherwise for you to be in curiosity and play, actually basically utilize the opposing forces in your brain.

It really it's not possible to be playful if you're protective. So those are those are the kind of the two opposing ends of trauma and healing, protecting yourself. You have to have your guard up. There's that wall that you want to build and kind of that locked down. But if you want to play, if you want to be creative, and curious.

You have to be open and free. You have to be ready to engage in these things, take small risks, you know, paint that terrible masterpiece that doesn't look good at all. These are examples of just being creative and curious and playful, and those are words I use a lot in sessions. It's a different way of looking at that brain mechanism kind of differently, understanding just what it looks like on the ground, you know, trauma and that force versus that play for freedom.

40:04:24

Dr. Katie Salyer

Healing is also very important to reconnect. Reconnecting for some individuals can mean socially, you know, reconnecting in other cases can be with faith. Some of these other beliefs that have since been feeling a bit shattered or just dimmed or otherwise differently impacted. In other cases, reconnection is about getting back into the body again. So much of the brain and body are protective and kind of creating that neck up and neck down, separate operating systems that it can be really helpful to reconnect in the body.

And so as you move forward in whatever state you may be in dealing with this cancer diagnosis, moving through treatment or otherwise, I encourage you to try to build a space in your world, an environment in your life that really incorporates all of these compassion, consent, creativity and curiosity and connection. And these different pieces are going to be what we use to be more precise about how to move from guilt and grief to growth.

So there's that statement growing through what you go through. Today I want to hopefully communicate this message that survivor guilt, grief, trauma even can be relatively normal. And survivor guilt itself is actually what we consider to be a moral injury. What that really means is essentially your value systems have been hurt, have been damaged, have been questioned, have been really, you know, brought to the brink.

And it's it's a it really calls into question that place of worth deserving and you know, it tests those those core beliefs or values about the world should be fair or people should be treated equally or should be afforded access to treatment or stability or financial security. You know, it really tests those values that we can hold. And those are the particularly justice oriented values. And survivor guilt can be a direct outcome from that. So when those values are tested, survivor guilt comes. And what that really can mean is ultimately survivor guilt. And that is just an expression of your values. It's a it's a way to recognize that that is a piece of who you are. You value humanity, you value fairness. And if we start to build a relationship and look at survivor, guilt is actually reflective of our values, it takes a slightly different shape.

It becomes less damaging and more about the weight of grief. Survivor guilt is really very much about grief. It is about those shattered values and then trying to make sense of them once trying to make sense of the world over again. Survivor guilt can in some cases be one way that brains and bodies try to restore or restore peace in a time of chaos.

It's a way to build order back into society. And in some cases, survivor guilt is just the Band-Aid that helps us do that. We really it keeps us grounded and in and it allows us to almost pretend that the world can be fair. Some people really it's such a really scary idea that aren't always fair

that survivor guilt is another way to just, you know, kind of put that Band-Aid over it and to restore order to a place in space when sometimes it's actually much more chaotic or sometimes based in luck or other invisible factors that we may just never really know.

And survivor guilt can be just one way that our brains and bodies help us to make sense of things. If we look at survivor guilt through this lens as being that moral injury, it presents an opportunity for us to maybe make friends with our feelings. This is something that a lot of trauma work will be built around, which is embracing or accepting these different, tough, heavy feelings as opposed to trying to fight them.

If you don't play tug of war, then, you know, if you drop the rope, suddenly you're not fighting against that feeling. You're instead embracing it and what that can look like in terms of survivor guilt is really saying to yourself, yeah, this is a reflection of my values. I don't want to remove that value from myself. I do want to really value humanity and fairness.

And this is in some ways a little bit of the grief and guilt that I have to bear in order to hold those values. It's a reflection of who I am, and I do not want to separate myself from those values. So this is one of my favorite slides. I'm going to try to be brief, but these are some home grown therapies and things that can be done any time you're moving through a time in life that can be highly stressful, potentially traumatic, really upsetting.

And I'm hoping to give some extra shout outs to a few of these different listings here. You can see that on the whole there are different recommendations for movement. There can be recommendations that are very clearly based on that curiosity and creativity kind of categories. You'll see others listed more in a sort of direct action. If there's a feeling of survivor guilt, what is something actionable that can be done in response?

So I'm going to highlight a few and maybe give a little bit more depth to a couple of them. So movement trauma is very much a body experience and moving that can be a really effective way to move that trauma and stress through the body. Sometimes that means gentle yoga. In other cases that can mean, you know, hitting up the rage room if you have to.

Movement is really powerful and it gives our bodies a way to release that stress. There are other sensory motor practices that sometimes can look like movement or otherwise. I like to mention this one because it's also got an interesting factoid. So we talk about our five senses, but actually we have eight. So we know those taste, touch, smell, sounds and I've already lost the last one, but the three that we never talk about are actually vestibular, interoceptive and proprioceptive.

And without getting into too much depth, that's actually these eight senses are really where we get the five S's for babies, you know, the swaddling, the, the shushing. So vestibular, internal, adaptive and proprioceptive senses are the ones that are about our bodies in the world and space, about balance, about an interoception is the sense that we have.

If I ask you, are you hungry right now? Interoception is just that intuitive knowing like, I'm hungry. Do I need to go have a drink of water? You know? So introspection is just a felt intuition. And so sensory motor practices can mean engaging these eight senses. So if you return back to having had an infant, you may yourself need to do some swaying.

There may be activity or a lot of sound and vibrational healing can be something to consider. Sometimes just loud singing, sighing, laughing, belly laughing and heavy sobbing. These are all things that actually can vibrate the body a bit. So there are a lot of creative ways to engage the

body in those sensory motor practices as well that will move you through some of that kind of stress release.

You'll often see me in sessions if I'm doing a lot of shaking or stretching. Some other things to consider would be grief rituals. They may be identified and practiced in a faith, or they may be personally created. There's no such thing as one way to grieve. You can write letters to your past self. You can write letters to, you know, the former identities you've held.

You can do grief rituals that involve anything from fire to shredding to, you know, truly holding a place in space physically where you go to connect with that part of you. Trauma work oftentimes uses this intervention of kind of asking you how you treat yourself or how would you how would you answer that if this were your best friend going through it?

So in this case, if your best friend was talking about feeling bad and unworthy for surviving, what would be the words of wisdom we'd share with them? So treating yourself like a best friend can be a very useful reframe to help you move through any stuck places. You. I don't know what to do with this or I'm feeling a certain kind of way.

Well, think about what you would advise for a close friend or family, a loved one. You can also see Pay it forward. This kind of fits in that category of thinking about actionable ways to directly respond to that survivor guilt. Do you have any advocacy you would want to do, any fundraising or political efforts or ways to support your local cancer support centers, for that matter, and nonprofits mentorship can be another way to really directly feel like you've done something in response to that survivor guilt.

And of course, you'll see expressive arts active participation. So really getting in there and getting dirty with the garden, you know, getting your hands all dirty, getting dirty with paint, in other cases, singing, making music, writing and journaling. These are all amazing ways to engage in expressive arts and being creative. And I do want to give an opportunity to also explain a little bit about solid professional therapies.

50:10

Dr. Katie Salyer

So talk therapy is what we all consider the traditional form of therapy. It's amazing and great and a wonderful way to get support. If you are in the position of thinking you may be encountering that trauma response, I want to make you aware that there are additional types of skills and interventions that are not always a part of traditional talk therapy.

So you may want to seek a professional out who might do what we call bottom up processing. There are lots of bottom-up processing styles that might be EMDR, brain spotting, somatic, experiencing yoga, a whole bunch of tired types. But you might want to take an opportunity to learn a little bit about that and find a professional that can provide that for you.

Exposure and response prevention is another way that trauma is often treated. I mentioned it here in part because it's something you can do yourself in small ways. What it really means is if you feel that sense of avoidance, you want to gently, slowly push back against that, go to your limit and take an inch further. So if you have not taken that street that passes your oncology office in three months, just ask yourself what would happen if you go ahead and just drive by, Maybe in another week's time you see what happens if you park in the parking lot so you can recognize there are these steps toward, you know, reversing that avoidance or just

reducing that sort of limit that that that avoidance and sort of trauma can those can kind of shrink our world. Some other professional therapies to consider our grief processing group support. These are very important to that cancer healing. And so I just want to bring your attention to them in addition to knowing about where you can find community.

So Sharsheret, Cancer Wellness Center are two amazing organizations that do wonderful work, connecting individuals with support, education. And so it's really key to know where you can find some great community and and find others that can really help you to make sense and move through that. So that place of survivor guilt feel connections in the world once again. And with that said, I will thank you once again for the opportunity to speak today, and I will check in to see if there's anything you want to talk about in terms of Q&A.

52:26:24 - 52:40:09

Aimee Sax

Thank you so much, Dr. Salyer. That was fantastic. I learned a lot, especially I didn't know there were three more senses. So it explains so much.

And I just love this. And if you want to unshare your slide so people can see us a little bit better. So I do just quickly want to say that quick disclaimer. 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 is not a substitute for medical advice or treatment for specific medical conditions. You should not use this information to diagnose or treat a health problem. If you have any questions that are specific to your medical care, we recommend that you speak directly to your medical provider. Always seek the advice of your physician or qualified health provider with any questions you may have regarding a medical condition.

But we did get some really great questions and private chatted and in the registration for tonight, we are running out of time, so I'm just going to ask one of them and perhaps I can talk, Dr. Salyer, to writing a few responses to the rest of them.

So we can share those with the recording. I think you really covered a lot of one of these. This one's a little bit longer, but basically talks about as a ten-year survivor who wasn't recommended chemo and radiation. So I've always struggled with calling myself a survivor because I'm not that kind of survivor, meaning a survivor of chemo.

And I struggle even more now being so distant from that time that struggles basically gotten more as time goes on. I feel like it makes me more nervous. Steer clear of the feelings I had, and I'm actually late for my annual scans. I think as a result, how can I process these feelings so I don't give in to avoidance?

54:27:18

Dr. Katie Salyer

That's a really great question. Yes. So this question really brings me back to this idea of a somewhat normal stress response, which is avoidance. Really. It's it can be one sometimes it can be an indicator of some trauma. And I can promise you, if you have been told you have cancer, that is that acute. That's acute. That's an opportunity for that acute trauma and that is itself enough to really burn itself into your brain and body in certain ways where it can cause that anxiety to grow, that avoidance to grow.

And the more that you feed that avoidance with avoidance, the more that anxiety grows to build more avoidance. So in this case, I would consider for that individual a recommendation to either do some of those personal, we call it exposure response prevention. So if you're feeling that need to avoid, I would wonder if you could build your way up with small steps.

It may be that you set a goal for one day not to necessarily make the appointment for your annual screening, but to just pull up the website. That's it. Don't overdo it the next day, maybe identify what the phone number would be or the steps would be so you can hear how you're setting small, more manageable goals. In other cases, it might be helpful to have some professional guidance.

You know, if you're describing a situation where that distance also can have you feeling disconnected. Right? We talk about that word a lot as well. And so that can be very closely related to either survivor guilt trauma as well. That feeling of being disconnect. And so having someone alongside to help you process that and make sense of it or connect again with the community or with your own, you know, the meaning of that experience can be really helpful. You know, again, I'm thinking about that sort of memorializing. We talk about grief rituals, but also memorializing that time and its importance in your in your life. So I'm not sure that fully gave a solid answer, but

56:35:20

Aimee Sax

I think that's really helpful. And I think, you know, the only thing that I would add is that the fact that they ask the question gives me a lot of hope. The fact that they register for the webinar gives me a lot of hope that they are thinking about this, you know, and we know that contemplation is the first step towards action. So I think that that gives me a lot of hope for this person. Well, I wish we could talk about this for, you know, a lot longer.

It's such a rich topic. And as you said, there are so many parts of the topic that could be their own webinar. So maybe we'll we know what we're going to plan for next year's webinar schedule. Thank you so much, Dr. Sayler. So informative and helpful. Special thanks again to Cancer Wellness Center for their support on this webinar.

I also again want to thank our sponsors, Daiichi-Sankyo, GSK and the Cooperative Agreement DP-19-1906 from the Centers for Disease Control and Prevention. Please take a moment to fill out the brief evaluation survey in the chat box. Now evaluations really do inform future programing, so thank you so much for taking a minute to fill that out. Please never forget that our social workers and genetic counselor are here for you and your loved ones.

Sharsheret provides emotional support, mental health counseling and other programs designed to help navigate you through the cancer experience. All are free, completely private, one on one. And our number is 866-474-2774. You can also email us at clinical staff at our share at dot org. Finally, I want to share our next national webinars with you. Join us this Friday for our next Shalom Shabbat to celebrate Hanukkah together on December 8th at 9:15 Pacific, 11:15 Central and 12:15 Eastern and the link to join in the chat and join the next in our Namaste Day Monday Yoga series with our Yoga for cancer teacher on Monday, December 11th at noon Pacific to Central and 3 p.m. Eastern. The link to learn more and register is in the chat box now. Please check our website regularly to see what other topics are coming up. The link is in the chat for that. You can also access the recordings and transcripts of all our past webinars on our website

Sharsheret: The Jewish Breast and Ovarian Cancer Community

from all of us at Sharsheret, thank you so much for joining us tonight and hope to see you next time. Take care.