THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'LIVE! At SHARE: Emotional Wellness in Survivorship'

Description:

The cancer experience isn't just physical—it's deeply emotional.

Join us for this special episode recorded onsite while filming our SHARE Project video series, exploring emotional well-being in cancer survivorship. Listen in as four blood cancer survivors share how their diagnoses impacted their mental health and what helped them cope. Key Opinion Leader, psychotherapist Julie Larson, LCSW, then joins us to discuss signs of emotional distress, the role of therapy, and how resilience and support can shape the healing journey.

Transcript:

Elissa: Welcome to *The Bloodline with LLS.* I'm Elissa. Thank you for joining us on this episode. Today we're filming on location for the SHARE project video series. SHARE stands for Stories of Hope, Adaptation, Resilience, and Empowerment, where each episode highlights impactful storytelling and conversation between key opinion leaders and blood cancer survivors, fostering a deeper understanding and connection among viewers.

The episode being filmed today is on emotional well-being in cancer survivorship; and we have pulled aside our Key Opinion Leader, Julie Larson, LCSW, to delve more into the topic the guests will be discussing. In addition, we'll be talking to the panelists themselves to hear how cancer has impacted their mental health and what has helped them to manage the emotional aspect of cancer.

We're going to start with our panel, which consists of four blood cancer survivors; and then we'll have a broader discussion on the topic with Julie. Let's get started.

<u>Casey</u>: Hi, my name is Casey; and I was diagnosed with acute lymphoblastic leukemia (ALL) at 31. So, I'm really good at navigating a crisis; so for the almost five years that I was fighting, it was literally survival – what could I do every single day to help the "team" because I thought of this as a team sport. If my team oncologists were doing everything they could to help me live, what can I do to help them in that process? And that meant showing up every single day and doing the things that I could do, like as far as exercise and participate in this journey just as they were.

So, that is really what kept me grounded and kept me going for that amount of time. But I will say once I was done with treatment, I failed at surviving. It broke me mentally, emotionally, physically. It brought me to my knees, and that's where I struggled the most. And I, for lack of a better comparison, had a nervous breakdown. And from that point on, it really made me address a lot of the issues that were going on even prior to cancer and to force myself to get to a better mental and emotional state, which was what I was desperate for.

There were so many things that helped me along the way to get to a better place. Number one, I started therapy, really intense therapy. I went on a healing retreat that I couldn't afford at the time. I started reading every self-help book that I could get my hands on. I asked a lot of questions to a lot of experts and started diving into PTSD (post-traumatic stress disorder) and trauma and kind of taking sources from other things and applying it to myself to find my path forward. There were so many things; but those were the majority of the things that helped me.

<u>Matt</u>: My name is Matt. I was diagnosed with AML (acute myeloid leukemia) at 25 years old. I think there's a huge impact on my mental health. There were definitely a lot of ups and downs. I think my emotional well-being was certainly dynamic. I was in a state of shock and disbelief when I first got diagnosed, but I would say I'm a pretty mentally strong person. I did athletics in my background on a Division I level, so, I just look for ways to push through and to find the good in everything. And I had a really wonderful support system that I think I could look to just to help me find the light when it was really, really dark at certain times.

Alfredo: My name is Alfredo, and I was diagnosed with ALL (acute lymphoblastic) leukemia at 24 years old. My diagnosis did affect my mental health in ways that, I felt my entire life was flipped around as a comparison as to the life I was already building at 24 years old. And one way that I've managed to cope with it is just, just looking at inspiration from my family and a few other male celebrities out there.

Simantenee: Hi, I'm Simantenee, and I was diagnosed with Hodgkin's lymphoma, Stage II when I was 22 years old. At such a young age, I just didn't know how to cope with the word, cancer. And then, it transpired into major depression. Once I was done with my treatment, I couldn't fathom the fact that I may not have a normal life; but that was not true. I wanted to go abroad and study. I couldn't do that. All my friends came to the United States for their higher education, but I was at home getting treatment. So, that led me to major anxiety and depression; and it was bad. It was terrible.

Music has helped me take out that anxiety and the depression definitely. I also used to write down my thoughts as it transpired into poems. That also helped me. So, the creative side of things, I think, helped me get through that pain, that anxiety. And you know the best part I had was I had friends who used to call me because, at that age, we were all done with our engineering and we all graduated and everybody was either pursuing their high studies or they just got a job.

But my closest friend, she used to call me every chemotherapy session, and she used to be on a phone call with me so that I could get distracted and I could bear that pain. So, yeah, music and friends.

Elissa: I am now sitting down with Julie Larson, LCSW, our Key Opinion Leader for this episode of SHARE. Julie is a psychotherapist who has spent her career working in oncology supportive care. She has a vibrant private practice working primarily with individuals under the age of 40 years facing an unexpected medical diagnosis.

Julie is a frequent speaker and educator to both survivor and professional audiences on the impact of serious illness at a young age, living fully after a cancer diagnosis, and resilience. Julie's clinical work integrates cognitive, behavioral, mindfulness, and narrative therapies. Working alongside her clients and audiences, she helps people identify inherent strengths and cultivate additional resilient behaviors to build confidence in the ability to navigate hardship. Welcome, Julie.

Julie Larson, LCSW: Oh, thank you. Hello.

Elissa: Thank you. So, as I mentioned in the introduction, the episode on SHARE is on Emotional Well-Being in Cancer Survivorship. Let's delve a little bit more into this topic. How can a cancer diagnosis impact mental health, both immediately and in the long term?

Julie: Immediately, it's an acute crisis, right? Everything shifts. Everything flips upside down, and you're gathering so much information not only on what is my diagnosis and what are the treatment options available to me but that you're also doing that at a time when there's unbelievable overwhelm and uncertainty and fear. And so, I think there's an acuteness to that initial stage.

And then through treatment, and maybe initially after treatment, it's kind of just getting through the day to day, right, figuring out what do I need to do to get from morning to night and recognizing and getting to know the medical team around you and the supports that are available to you. How does my body respond to treatment?

And then, I think there's a difference in that long road, right? That when people finish treatment or for those who are living with an advanced stage diagnosis where they're going to be managing their treatment always, there's the awareness suddenly that, "Oh, I'm changed."

Elissa: Right.

Julie: There's something different about me. I'm not the same as I used to be; and there's maybe sadness in that for sure or in grief; and we're not even initially aware because of the chaos and acuteness of that first time how much has changed.

Elissa: Right, and it's almost changing in so many different ways, right? I mean, you have physical changes, emotional changes, financial changes, most likely. Changes to really almost every aspect of your life. And that can be really hard to navigate.

Julie: Yeah, and we're biologically programmed to be aware of what's not working, right, like what we're missing, what feels dangerous, what feels gone. So, we notice all of that first. And there's quite a lot of grief and sadness in that. You just said many different areas. So, some people really are very much hit and affected by how their body is just very different to them.

Elissa: Yes.

Julie: And other people are recognizing that their career trajectory has made a huge change or that for younger survivors, maybe this idea of family and fertility is different; and there's grief in that.

I think the journey is beginning to figure out how cancer changed you in a way that got you through.

Elissa: Yeah, absolutely. And just to note that all of those things that you just talked about too, that you can be affected by all of them, all at the same time it seems, which can just be very hard, with body image issues, not recognizing the person in the mirror. I think it has such a tremendous effect.

I remember when I was going through my treatment for acute myeloid leukemia (AML). I was just shocked that I was like who is this? I don't know who this is staring back at me, and that just hit me in a way that I never anticipated it to hit. And along with those other things that my career was on hold, and of course that comes with financial issues. There's other physical issues going on. It hits your emotional well-being like a ton of bricks.

Julie: Yeah. And we want to fight that, right? We want to get it back. We want to resist that initially, right? So, some of the mental distress is our resistance with this complete upheaval. "I don't like it. I'm going to get my body back. I'm going to do X, Y, and Z; and I'm going to do these things in my career." And then suddenly we are like, "Okay, there are pieces that are unequivocally gone. They're just gone. They're changed." Yeah.

Elissa: Yeah, and I know people don't like to use that term, "new normal," right? It's difficult for a lot of patients and survivors to think about that. But at the same time, it is somewhat of a new normal; I mean, you have to kind of figure out what your life is like now, not what it was prior to diagnosis. There's that little break in time. Before diagnosis, after diagnosis.

Julie: And when we think about grief work, grief is many different things. It's a collection of experiences from denial and numbness and bargaining and anger and the depth of vulnerability of sadness. But, what you're saying to me sounds a bit like acceptance. And acceptance is not like, "Oh, and now I am grateful, and I have found the meaning, and I get it and I am so proud of myself; and it's sunshine and rainbows, and I can see the horizon line." Acceptance, truthfully is, it is. Here's where I am, and I can't deny that, and I can't bargain and change it. And it makes me feel sad, but here I am. What now?

Elissa: Yeah, because you still can feel all those emotions that come in with it, even if you have, to some degree, accepted that my life has changed. Right? It's just different and I probably can't go back to what it was before. But I can still have all these emotions that come with that. And actually, that leads into my next question.

What are some signs that someone may need additional emotional support after treatment?

Julie: That's a good question. I think our world, our culture is uncomfortable with hard and heavy feelings. We don't like it.

Elissa: Yeah.

Julie: Nobody wants to feel it. It doesn't feel good. We don't like to see it in the people that we love. We don't want to see that struggle in the people that we love. We want everyone to feel better.

And I say a lot in my office. I am listening closely. Do the thoughts and feelings that you are experiencing match the circumstances that you are going through. And I think that's also part of the adjustment of cancer. It may be very abnormal for you to have a hard time making decisions or to feel sadness to this degree or to feel like an agitated uncertainty. That may not be your norm, but it is totally normal for a cancer survivor. So, part of the distress is normative, and it makes sense, and it's understandable, and we have to allow and make space for that and grieve. You asked when is it a problem?

Elissa: Yes.

Julie: Or when is it maybe a sign that we need to pay closer attention to it? What I'm listening for are kind of the extremes; and when sometimes ruminating, thinking, or a flatness and a heaviness is getting in the way of functioning.

Elissa: Yeah.

Julie: If there's such a state of suffering and sadness that people are withdrawing and constricting and it's getting in the way of relationships, it's getting in the way of basic functioning and connection, then I want to pay attention to it. If the spinning, anxiety, and ruminating is leaving absolutely no room to focus and concentrate on the day to day, then we've got to look at that a little bit more, right?

Now, there's also a space where I don't think you need to go to therapy if you're struggling outside of the range of normal. I think therapy is a space, wherever you are, it becomes a place where you are dedicating that time to looking more closely at how you're feeling because we live busy lives; and even cancer survivors live busy lives, right? You are going to treatment, you are managing side effects, you are figuring out what to eat, should I walk/should I not walk? All these different things. So, therapy becomes a protected hour, or whatever it is, where this is all that this is about is really letting myself notice how I'm doing.

Elissa: Yeah, I remember in treatment, I noticed that something was a problem around the holiday season because I know how I normally am during the holiday season, particularly around Christmas, around Thanksgiving. And I found myself not finding the joy of the season, and I had always found the joy of the season. I love that time of year; it one of my favorites. And at that time, I was like, "Something's not right to where I feel like I need to address this." I need to talk to somebody; and I went to my social worker and I had just finished treatment in early November and she said, "You know, it's totally normal to completely break down once treatment's done. You've done all you can do to survive, and now treatment's done." And it's kind of like, "Okay, you're done. Go on your way." I was like, "Well, I don't understand these feelings. I don't know what's going on. I don't know how to move forward in my life, and I'm not finding joy in this time of year, and something's wrong." And I was glad that she told me that that was totally normal. That was something that can absolutely happen, and it happens to a lot of people. And so that normalized it for me, but it was still like, "Okay, I still need to find some way out of this. I need to find some way forward."

Julie: Yeah. There is some degree of relief in knowing that the distress that I feel makes sense, but I still feel it. But I still need support. I need to know what to do with it and how to kind of move myself through it.

Yeah, you mentioned, that that hit you within a month, six weeks after treatment. And I say to people, I feel like I say it all the time, and yet it is still a message that is not getting to people in treatment or newly diagnosed. It is not uncommon at all. In fact, I think it is more common-

Elissa: Yes.

Julie: -that the mental and the emotional impact of a cancer diagnosis really hits when treatment is over. And there's a sense of like I'm done. But then it's your whole life-

Elissa: Yeah, now what.

Julie: -and now what, yeah. And I'm different, and everyone around me is happy and cheering, and I'm recognizing privately and quietly I'm not myself.

Elissa: Yes, yes, exactly. And I think that's the thing is you've seen the whole rest of your world move on. And you're still here. You're still stuck in this space and still stuck as this person who has cancer or who has just finished treatment or is trying to find some new way in this life where things might have paused or stopped completely. Maybe you can't go back to the career you were in. Maybe you can't go back to school, or school has stopped for the rest of the school year. And then, what do I do now?

Julie: And then I add on top of that, it's not easy to dream. Before that you could dream. Oh, I'm going to do this; and then I'm going to become this. And many survivors have a hard time expanding that horizon line. It feels very, very scary to think about the future, right? And you've really been conditioned to think treatment to treatment or, at some point, scan to scan. So, to think about a bigger picture for your life feels a bit reckless, maybe dangerous, right? So, we want you to begin to kind of grab onto who are you now; but how do you do that and also stay present and centered?

Elissa: So, you finished your segment of SHARE just a few minutes ago. Holly was talking to you as a Key Opinion Leader about emotional well-being. And there was something that you said that really stuck out to me. You said, underneath an uncomfortable feeling is an unmet need. What does that mean?

Julie: Well, let's flip it around. Can you think of a time in your life or a moment where you just feel good, you feel good. You feel blessed. You feel happy. You feel joy. It is quiet maybe, and you just feel great.

In those moments, your needs are met. Maybe it's a time you're surrounded by your family; and you're looking around and you're like, "I am so loved." Or you're maybe just kind of on a beautiful beach looking at a sunrise or a sunset. But in those moments, your needs are met.

So, the reverse is true. When we feel distress, when we feel agitated, when we feel impatient, when we feel dread, when we feel overwhelmed, we feel lonely, that we're needing something, something's under there that we need, and so we have to play close attention to what that specific feeling is because that can begin to help us decode what that need might be.

Elissa: Okay.

Julie: In terms of grief, you might be longing for your old body.

Elissa: Yeah.

Julie: Right? Or you might be longing for the zip and the carefreeness and the nonchalants that you had before a diagnosis. But what could be under that? Could it be a sense of freedom? Could it be a sense of autonomy? And then are there other strategies where maybe we could feel and meet that need in a different way? But, it's important to know what the need is.

Elissa: Yeah, I like the idea of really taking a step back and trying to figure out what that need is that you are missing. And again in a more specific way, like you talked about, not just I miss my old life. I miss having a life where I didn't have to think about death. I miss the body that I had. I miss being able to just cruise through life without all these extra things going on, wondering if I'm going to relapse, wondering if I'm going to get a secondary cancer. Trying to find my way forward, but really thinking more specifically than that, right? What was it about those things that I miss?

Julie: And also, this happens in therapy too, right, or with a good friend, So, you can have these safe spaces and these conversations in the therapist office. You can have them also with a friend that challenges you and listens to you in just the right ways too. But we begin always with what's hurting.

Elissa: Yeah.

Julie: And, in my office, I listen closely to that. We're very tuned into, because it's not comfortable, what's not working. Can we begin to figure out what is?

Elissa: Yeah, yeah. I think definitely addressing what is working is really important.

Now you mentioned talking to friends or talking to family. So, how can young adults with cancer communicate their emotional needs to their medical team or their family or friends because a lot of young adults find it difficult to really be open and honest about the things that they need emotionally because I feel like we always talk about those physical needs, right? It's difficult to walk. I'm fatigued all the time. I'm in pain. But we don't necessarily talk about those emotional needs. I found it difficult for me to talk about my emotional needs with my medical team. And I felt that sometimes my family and friends didn't always understand. So, how can young adults communicate better with the people in their lives or their treatment teams?

Julie: It may make sense to also pause and think what are you wanting? What are you needing in talking? Are you talking so that you're understood? You need someone to understand you? Are you talking because you need information? Like I need to get answers to these questions? Are you talking because you're standing up for yourself? Why are you talking, right? What are you hoping to get on the other side of it?

And then there might be a benefit in thinking who's my audience for this? Because I think there can be disappointment and frustration when we finally do muster the ability to share what we're feeling; and it's met with either like a deer in headlights, like somebody that doesn't know what to do with that or clichéd statements of like, "Oh, you're going to be okay.‟ It just doesn't match.

So, then, where's our audience for that? And that's where I've, throughout my career, sat in so many support groups where I watch. I mean, I sit back in that room because my voice is less necessary, right?

Elissa: Right.

Julie: It's watching the peer to peer talk to each other. And when you feel heard and when you feel understood, maybe there's nothing somebody needs to do.

But you just need to feel heard. So, how do you do that? I think there's courage in that honesty and you may not know exactly what to say initially. But maybe resist putting on a happy face if that's not really how you feel. How do you challenge yourself to be honest? The question might be, "How are you doing?" "Fine." Ah, is that an opportunity for you to say, "You know, it's hard. I'm struggling with this X, Y, or Z." And just beginning to cultivate that skill of putting words to what you're experiencing. If you don't have words, how do you begin to maybe write and experiment on your own with how am I understanding how I'm feeling?

We communicate nonverbally. So many people may not have words, but they sit side by side, thighs touching on the couch with their mom. And that says something, right? That says I need you.

Elissa: Yeah, I think there's something to be said too about making sure that people also understand what you are needing, whether you just need to vent or cry to somebody or if you just need somebody to just sit with you in silence.

Julie: Yeah. Oh, you're making me think of something. You're making me think of a client that I have that I love this. Because I've heard so many different things throughout my career.

She didn't always want to talk to her friends, right? She didn't want to go there all the time. But yet she knew they were very interested in how she was, and she did want to continue to kind of keep her support group close. So, they came up with an emoji code, and her friend group would like text in the morning; and she'd just send back an emoji that kind of signified something. Like fire was, "I'm angry. I'm irritable. I'm low patience. I'm low frustration tolerance today." One was , a balloon. It was like I'm playful I'm silly, you know, whatever it meant; and she would send, and they all knew in her emoji a little how she was that day, and that was really helpful to her.

Elissa: I love that.

Julie: Right.

Elissa: That is such a good idea

Julie: They had like emoji code.

Elissa: Yeah, and it is so good if you don't really want to talk.

Julie: And you don't know the words to say.

Elissa: Exactly. Exactly. I mean I love the emoji idea. That is, that is just perfect because, yeah, I mean sometimes too you just want to get across in some way how you're feeling. But you don't necessarily need it to be fixed right now.

Julie: Yeah.

Elissa: I don't need you to fix whatever the problem is. I just need you to be there.

Julie: Yeah.

Elissa: Just be present.

Julie: Yeah.

Elissa: And I love that they're checking in with her in the mornings just to see how you're doing that day. I loved getting checked in with in the mornings when I was in the hospital. My parents would text me every morning. "How's things going? What sounds good to eat today?" That was the big thing.

Julie: Yup.

Elissa: What can you eat today; and we will bring it to you.

Julie: Yep, concrete.

Elissa: Yes.

Julie: And that signified to you they're there, they care, they want to be there with you.

I have another client who they send GIFs or memes to each other. If you can't say it, could it be the case that somebody else already has, right? Like is there a meme out there that is fully capturing exactly what you feel today? Use that.

Elissa: Exactly, the GIFs in particular. Those are perfect to just, you know, go back and forth and say what you can't say.

Julie: Yup, yup.

Elissa: I love that.

So, you talked about all these different people in somebody's lives. What role does community and peer support play in maintaining emotional well-being during and after cancer treatment?

Julie: I think that it's peer support, I'm a huge believer in that, in peer support. And I think initially people are like, "I don't need a support group. I don't want to go in and be around people who are sad and upset." And listen, support groups are like going into a dinner party. There are some dinner parties where you feel awkward and weird and you don't want to be there, and that is fine. But you should still try another dinner party because you might walk into the next dinner party and you've had the best conversation that you've ever had, and everybody stays well past dessert. So, if you've gone to a support group and it wasn't great for you, I'd keep looking because I have sat in too many to not believe in the profound power of that version of support.

And I think in there a couple things happen. I don't know if you were in a support group through your journey, but I think a couple things happen. I think we suddenly realize that what we feel is okay. Like, oh, my gosh, I'm not the only one. I'm not abnormal. Other people are feeling the same thing. Holy cow, I thought I was doing really bad. No. Oh, my gosh, other people think and feel the same way? That's helpful.

And then just even noticing that someone else is also struggling. There's a concept called universal suffering, and universal suffering is this idea or this reality that there is somebody else in their quiet corner of the world who is also figuring out how to get out of bed in the morning.

Elissa: Yeah.

Julie: And going to their closet and nothing fits the way that it used to. And that person may be seven states away. But just knowing that there's somebody else out there who is also figuring out how to get from sunup to sundown somehow helps.

Elissa: Yeah, absolutely. And that's what I love about SHARE is that the panelists are so real with what is going on in their lives and how they have navigated survivorship and all different kinds of aspects in it. And there were a lot of sad stuff shared today in the episode, but there were also very beautiful things and wonderful things that have come out of this. They've managed to navigate their way through it. And that is wonderful about having those people that you can connect with.

And I find in the cancer community, it is almost so easy to be able to connect with somebody. They just get it. With very few words, they just somehow seem to understand, even if they haven't had the same treatment or gone through exactly the same things. You usually can find something that will resonate and that you have had some kind of similar experience and really connect and I do find it's important to see those struggles and know that, "Hey, I'm not alone in this. I'm not abnormal. I'm doing okay; and look at them. They're doing okay. They're doing okay now. Maybe I can be doing okay."

Julie: I love in the program Holly asked the question to each of them. What would you tell your newly diagnosed or yourself that was just beginning? I ask that in my office a lot too, and I love that storytelling question because of two things. I think, one, it immediately illuminates that you're not there. You are no longer in the middle of that darkness. You are not experiencing right now, in this exact right now, you are not in that place that you were. So, you are not there. That's first.

And then two, it's really calling on or demanding on you to really sit back and think, how'd I get here, and what did I learn about myself? And in what I've learned about myself, what would I then share or shed light on to my earlier self? I mean, what a moment of being able to articulate and notice your own strength, your own growth, the things that you have discovered about you along the way that you want to tell your earlier self. I mean there's such growth in that.

Elissa: Yeah, yeah. I think that is a very good homework assignment, as well, for our listeners today-

Julie: I love homework.

Elissa: - what would you tell your newly diagnosed self?

Julie: What would you tell them? What do they need to know?

Elissa: Yeah, absolutely.

Now, let's talk about therapy. So, some patients seek out therapy when dealing with a cancer diagnosis. Others are hesitant or unsure of therapy. What role can therapy play for a cancer patient, and when is the best time to look into therapy?

Julie: At any point. I meet people at any stage where they are in the cancer trajectory. So, at any time somebody can walk through those doors and find benefit in that sacred hour or that safe space to talk with a therapist.

What's happening in therapy, what's that like if you've never been to therapy, or maybe you've had a not so great experience with a therapist. I think, first and foremost, you want to feel understood. You want to feel that when you speak, that person across from you is working very hard to understand you and cares to understand you.

I want all of the people that walk into my office to feel somehow different when they leave. That that was meaningful to them, helpful to them in some personal way, whether they feel lighter, whether they feel more hopeful, whether they feel proud of themselves, whether they feel relief and a little bit calmer, or whether they suddenly kind of had a lightbulb moment and seen something. I say a lot, either I'm listening and very curious to hear their story; and/or I'm often just simply holding up a mirror and reflecting back what I'm listening to and seeing in you.

And I think all I'm doing is telling you what you just said to me. But it's surprising to me how what I say or how I respond just can be lightbulb moments for somebody who hadn't put it together. When I say something like, "I am noticing in you how every time you're met with this frustration or this anger or this irritation, it drives you to speak up for something that you want from your medical team. I'm noticing every time you tell me that what you do with that is then you take it, and you're an incredible advocate for your needs. And that anger or that frustration is driving you. It's giving you the energy and the courage to do that. Are you noticing? "I never thought of it that way."

Elissa: Yeah.

Julie: But I'm not really doing anything. I'm just showing, I'm seeing this in you. Are you seeing it? And then you walk out, and you're like, "Oh, I've got this skill. I can channel this uncomfortable feeling, and I can use it in a way that moves me forward."

Elissa: That's what I loved about therapy was that it does provide you those strategies to cope with this, to move through the emotional impact of cancer. What I did was told to journal because I had never processed any of it emotionally until after I finished treatment. And then it all kind of came to me all at once, and so, my therapist said, "Hey, I want you to journal. I want you to go from the beginning, just before diagnosis when things were starting to ramp up, and write about each part of it and how you felt. And it's okay to feel whatever you're going to feel, and it is okay.

And I felt that that was really helpful because it finally helped me process through each bit of my diagnosis through the treatment, the bad parts, the good parts, the okay parts. And, I felt like I could move forward; and I had these strategies to deal with triggers, to deal with anything that was happening that didn't sit well with me to look for that unmet need.

Julie: Yeah. Well, and you mentioned that you began to notice your distress around the holiday season, right? So, I think some of the work too is recognizing I'm going to learn these skills, I'm going to begin to be more self-aware, and learn how to take care of myself. But there will be triggers along my road.

Elissa: Yes.

Julie: And as I begin this journey, I have no idea what those are. And sadly, you don't often discover a trigger until you've been triggered. But then you know that, and you take gentle care around yourself, around that. I use the metaphor a lot of "driving in the rain"; and if you are literally driving in the rain on the highway and it starts to pour, I hope you drive different.

Elissa: I hope so.

Julie: Right?

Elissa: I hope so.

Julie: I hope you drive different. I hope you turn on your windshield wipers. I hope you slow down. If it's that crazy rain, maybe you put on the hazard lights, right? So, same thing. Like when we begin to notice our distress, we get to say, "Okay, I'm not 100% today. I can't drive the same. I've got to lower my expectations today. I've got to move slower. I may take a couple things off my calendar that I had because I'm just not me today."

Elissa: Yeah, and that makes sense. Now, we do see that there's benefits of therapy; but professional therapy can also be really expensive. And sometimes it's out of reach for patients, particularly young adults with cancer. So, what are some other ways that patients may manage their emotional well-being during treatment and into survivorship?

Julie: I think one of the things I would say first is if you get into some of these cancer-related support groups, many of them are facilitated by a professional.

Elissa: Okay.

Julie: So, can you enter into that space with a different lens? One of, I want to connect with other peers. But every nugget or gem that that social worker drops or facilitator drops, that's my free therapy. Right there it is. There's my free therapy. Or somebody mentions what they got in their therapy. Oh, there's my free therapy again. Just keep collecting it. Listen for the little Easter eggs when people talk about their therapist. A lot of therapy is your own work and your own self-reflection, right? So, how do you begin to think about that differently in that way?

I think that there are tons of mental health and self-care/self-help books out there around awareness, around even types of therapy modalities like cognitive behavioral therapy or mindfulness stress reduction. So, if you look into those things and begin just to educate yourself and educating yourself about that, you're going to start to do that for yourself. Begin to thought watch. Begin to do those things.

I think there's a lot of nonprofit organizations that do provide publications and resources and education around the normal response to cancer, the stress that we feel. And sometimes, not unlike learning about your blood cancer diagnosis, sometimes understanding the mental and emotional impact of the cancer diagnosis, just educating yourself about that, helps you feel better. Educating yourself about what PTSD is helps you be like, "Oh, I get it, and then now what?" You can begin to read and educate too. Those things are options.

Elissa: Yeah, I'm really glad that you went through that because it can be, again, out of reach for patients to do professional therapy. And so, it is good to know that there are things out there, whether it is peer support or going online and watching a guided meditation video. You know, those are great to listen to; and we have, we have a "How Do I?" video that talks about managing your anxiety through breathing exercises; and it takes you through a whole breathing exercise activity just to calm down.

Julie: Correct.

Elissa: And calm your nervous system. It's good to know that there are so many different things out there if either profession therapy is unaffordable or it's just not something that somebody is interested in-

Julie: Right.

Elissa: -because not everybody is interested in it. And that's fine.

Julie: Kind of back to your affordable piece too, can we in any way change the thought around affordable? You know, some of these even meditation apps that exist out there, they have a yearly subscription often to them that is up to 100, maybe even more than $100 for the year, which feels like a lot for an app, right?

But let's reframe that. We buy shoes. We buy clothes. We buy things that sometimes we indulge on and we give ourselves. This is worth it. So, yeah, there's a little skin in the game there, but you're worth investing in. So, it might not be that you can pay a certain amount of fee for out-of-pocket therapy weekly; but if you can get that app that you can hold onto a full year, it may seem like a lot, but you're investing in you too and that's important.

Elissa: Yeah, yeah.

So, our final question today, Julie, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." What would you say to patients and their loved ones to give them hope after a cancer diagnosis?

Julie: Hope, what a word, right? I love it so much, and yet I'm delicate with it because I think there has to be a place when you feel comfortable believing there's hope. Initially, it feels like, whoa, hopeless. But I say I think we all can believe, if you've sat in this work for any amount of time, and I've done this for over 20 years, there is always hope. There is always hope. It changes. And the hope might be little. Sometimes it's the small moments that are so big, right? I want to hope to get to this holiday and have all of my friends around me. I want to hope that I can find a dress that I wear to this event that makes me feel confident and good. I want to hope that as my hair grows back, that I begin to feel more confident and more calm in my body. We can keep changing our hope, and maybe that's related to that unmet need, right? Absolutely believe.

Elissa: Yeah, and that is exactly why we do this podcast. That is why we do patient education materials for The Leukemia & Lymphoma Society, for blood cancer patients and caregivers, to give them hope.

Julie: Yeah.

Elissa: To find all these different ways that they can watch videos, listen to podcasts, do all these things and connect with other people and be part of the wider cancer community. There's a huge cancer community waiting for each and every one of them – patients, caregivers, survivors – and that can provide so much emotional support in so many different ways.

Julie: So many different ways, correct, yeah.

Elissa: And so thank you so much, Julie, for sharing all about mental health and emotional well-being after a cancer diagnosis and through survivorship and beyond. We really appreciate you joining us today. I am excited for this episode of SHARE to come out, so I hope that everybody watches and hopefully will find so much connection and resonate with this information. And so, again, thank you so much.

Julie: Oh, it's an honor. I sit in the presence of so much resilience every day.

Elissa: Absolutely.

Julie: And what, what a gift to be able to talk about it with you, thank you.

Elissa: Thank you.

And thank you to everyone listening today. *The Bloodline with LLS* is one part of the mission of The Leukemia & Lymphoma Society to improve the quality of lives of patients and their families.

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In addition to the Lounge, we could use your feedback to help us continue to provide-engaging content for all people affected by cancer. We would like to ask you to complete a brief survey that can be found in the show notes or at TheBloodline.org. This is your opportunity to provide feedback and suggested topics that will help so many people.

We would also like to know about you, and how we can serve you better. The survey is completely anonymous, and no identifying information will be taken. However, if you would like to contact LLS staff, please email TheBloodline@LLS.org.

We hope this podcast helped you today. Stay tuned for more information on the resources that LLS has for you or your loved ones who have been affected by cancer.

Have you or a loved one been affected by a blood cancer? LLS has many resources available to you – financial support, peer-to-peer connection, nutritional support, and more. We encourage patients and caregivers to contact our Information Specialists at 1-800-955-4572 or go to LLS.org/PatientSupport. If you would like to see the SHARE videos, please be sure to visit LLS.org/SHARE.

And lastly, if you would like resources available for mental health after a cancer diagnosis, please visit LLS.org/MentalHealth.

Thank you again for listening. Be sure to subscribe to *The Bloodline* so you don't miss an episode. We look forward to having you join us next time.