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The Bloodline with Blood Cancer United Podcast

A podcast for patients and caregivers

Episode: 'The Bloodline Live!: Redefining Resilience'

Description:

Recorded onsite at CancerCon®, a young adult cancer conference presented by Stupid Cancer®, we talk about what resilience really means after a cancer diagnosis, and why it's not about always being "strong."

Join us alongside Sam Brotkin, PhD, a clinical psychologist at Bull City Behavioral Health and Chelsea Kaye, LCSW, an Information Specialist at Blood Cancer United. In this episode, we share compassionate, practical strategies for building lifelong resilience. Learn how to manage expectations, find trusted support, and give yourself grace exactly where you are today.

Although this discussion comes from a young adult cancer conference, the insights shared are relevant across all ages and experiences.

Transcript:

Elissa: Welcome to *The Bloodline* with Blood Cancer United. My name is Elissa, and today we are podcasting live from CancerCon, a young adult cancer conference presented by Stupid Cancer.

This year, the conference is taking place in Seattle, Washington, and is attended by over 300 young adult cancer patients, survivors, and caregivers, as well as nonprofit and healthcare professionals.

Blood Cancer United is a proud sponsor of this annual event, which is attended by people affected by all cancers. However, blood cancer patients and survivors often represent around 40% of the total attendees each year. Even though this episode is recorded at a young adult conference, our topic today is relevant to all ages of cancer patients, survivors, and caregivers. So, be sure to stick around for this episode.

In this episode, we will be talking about resilience after a cancer diagnosis. We are joined by Dr. Sam Brotkin and Chelsea Kaye. Sam is a licensed clinical psychologist who currently provides clinical care to children, adolescents, and young adults with cancer at Bull City Behavioral Health in Durham, North Carolina. He co-developed PICASSO, a one-on-one peer support intervention and Bobby's Coaches, a peer-to-peer support program for AYA cancer patients at the Duke Cancer Institute.

Chelsea, is a licensed clinical social worker in Portland, Oregon, who joined Blood Cancer United as an Information Specialist in 2024. She has extensive experience in pediatric palliative care and oncology and also has a private practice where her oncology background has helped her work with cancer survivors and family members. Welcome, Sam and Chelsea.

Chelsea Kaye, LCSW: Thanks for having us.

Sam Brotkin, PhD: Thanks for having us. Excited to be here.

Elissa: So, before we get into our conversation today, let's define a term. Your session was titled, "Build to Bend: Practical Approaches to Strengthening Resilience." What does resilience mean when we're discussing cancer diagnosis and survivorship?

Chelsea: I mean, I think, from a context of a cancer patient, resilience is something that they're going to move into; and it's a process that is going to be part of their experience because cancer is a hardship in many ways. And so resilience helps them kind of identify and move through and learn and grow.

Sam: Yeah, when Chelsea and I started working on this presentation, our first response was we weren't really big fans of the term "resilience," to be quite honest. We see there's a lot of pressure and expectations placed on AYAs, caregivers, really all cancer patients today on how they're supposed to appear. And one of those expectations often being placed is one of having to be strong, having to have it all together. And when we approach resilience, we looked at the literature and really connected with Dr. Abby Rosenberg's work; and she defines resilience as a process. One that changes over time and a skill that can be cultivated – very different than in how, our society, we talk about resilience. Often, a trait we're just either born with, we either have, or we do not have. And here in our session, our goal was really to challenge how we think about resilience and really rely on what we know in the literature to support patients as they move forward.

Chelsea: Yeah, I think that the opportunity to explain it to them as just that, as a process, something that you move through that's fluid to help shift their thinking, make it something that they can feel like they can take with them and better understand.

Elissa: That's great. Now, you mentioned people saying "strong and brave"; and, Sam, you started off the session today with a question to ask who has heard those terms directed towards them. So, "You're so strong." "You're so brave." You know, during their cancer journey. This was followed by a discussion on what their reactions were to those comments. That was certainly a very loaded question in the AYA cancer community, as I think we've all had someone tell us how strong and brave we were. But everyone responds differently to that comment. How were you finding the reaction today when you asked that question? And then, what was your reasoning for starting this discussion that way?

Sam: Yeah, of course. So, I think about every participant raised their hand that they were at some point told that they were strong or resilient in their cancer journey altogether. And resilience, it's a heavy word. It's a messy one. I think we have a lot of feelings that come up when we hear the term resilience.

I saw many folks raising their hands, particularly when we asked about some negative feelings towards that label and that phrase; and for many patients I work with, often when they hear that phrase, they describe feeling somewhat isolated and misunderstood. It's somewhat of a term that can be used to separate someone from someone else. And our goal today in really naming that was to really differentiate what society deems as resilient versus what we really know from the psychological literature what resilience really means.

Elissa: So, this conversation ended up leading to a discussion about pressure put on AYAs with cancer, as well as those who care for them, and then the mask that we find ourselves wearing. And to provide a little context for our listeners, so you provided us with paper masks; and we were to write or draw on the outside words or phrases or pictures that made us feel how we were projecting outward. And then on the inside, we went in and wrote, maybe, how we were really feeling. Could you share more about that?

Sam: I think often in my work with patients, it's one of the first places we start. There's so much pressure that is placed on patients and their loved ones that they're supposed to act a certain way and know what they're doing and appear strong. And in order to do the hard work, we've got to talk about what's hard. And being able to identify what are some of those expectations that patients have noticed that have been placed on them, ways that they feel like they should be appearing in front of others and really naming that, first and foremost.

And the reason being is in order to do the hard work, we've got to be able to take down those walls that we place, whether it be in front of us to other people or whether that be in front of ourselves. And so, our goal today was really to be able to name those masks and allow participants to be intentional in, really, what they wanted to do with that mask.

I did hear from one participant who wanted to stab the mask, some participants who wanted to rip the mask and throw it off and really be able to be very mindful in how they wanted to present their own masks, or not, when thinking about entering a conversation about hardship.

Chelsea: I think it was nice to see, as we talked about just setting that expectation that folks enter as they are. But who they are, that mask is part of that story. It's part of who they are, and so we wanted to just acknowledge that and give space for them to kind of reflect and understand that. And we did have patients, I watched during the session, tearing up their masks or adding to their masks and changing them as they went, which I thought was really cool to see.

Elissa: I noticed in my table that a lot of reflection of needing to be positive all the time and needing to be happy-

Chelsea: The happy place.

Elissa: -and everything is rainbows and roses. And on the inside, you're feeling alone and sad and tired and feeling like you can't really show that in an outward manner.

I just really loved how you did that; and hopefully, it's something for our listeners to really think about how you're projecting on the outside and how you feel you need to project on the outside versus what you're feeling on the inside and thinking about those.

So, Chelsea, you then talked about the resilience process. Could you tell us more about that and what it means to cancer patients and survivors, as well as their caregivers?

Chelsea: Yeah, we talked a lot about the resilience process through the lens of Dr. Rosenberg and the Venn diagram she uses which really kind of looks at three different spaces within that process – the first being kind of that getting through, which is that acknowledging we're experiencing a hardship, normalizing that, having an emotional response and getting through and knowing that that's going to look different for each person and day to day. We also looked at the idea of kind of harnessing our resources and talking about what those resources are. And then the last part of that process just being that kind of looking and learning and reflecting and meaning making of some of the things that we've moved through.

And the great part about the resilience process is just that. It's that we are moving through it throughout our lifetime, and it's going to look different at different points. And some days we might be, in that getting through space; and then we switch over to harnessing resources or we've got feet in both. And I think it's important to understand that there isn't a right or wrong. It is a process; and as humans, we're all kind of moving through it and figuring that out. So, figuring out kind of what do we want from this process, where are we hoping to go, but where do we find ourselves can be really powerful.

Elissa: Yeah. Our next topic was on resilience resources. So, you separated them out into categories: internal, existential, and community and social. Would you expand more on each of these; and what are some examples and strategies that patients and caregivers may use?

Chelsea: Yeah. We had some great lists today in the session coming through. The three categories being the internal is the action, the what we do; and that can look like, you know, engaging in art. Somebody shared, like, "I realized all these activities are things I could take outside. Take a walk, change my environment." And then with the existential, that's the what we think that might be using a mindfulness skill. One of the things a lot of the patients were sharing was just liking the idea of talking to myself the way I would talk to a friend. Giving that kindness to myself, just like I would give to somebody I care about.

And then the last category being the communities and, the who/what supports we're bringing in. CancerCon was that for some of the patients. Right, that's why they're here, to build that community. I think it was really exciting to see people growing their lists, building them, and figuring out what they could take forward with them.

Elissa: Yeah, yeah, absolutely. I remember when the one participant brought up the talking to a friend, right, so if your friend was going through what you're going through, how would you talk to them? Because I think we're used to kind of beating ourselves up a little bit about things. And I was like, "I wouldn't say that stuff to my friend, who was going through this. I would be kind and supportive and trying to find ways to lift them up versus bringing them down."

And so, I thought that was one thing in particular that was just so good to think about. It was, like, how would I talk to a friend about this? And then, of course, the community aspect. In the small group discussions, one person was next to me; and she was saying, "I don't know how to connect with people." I'm like, "You know, you're here at CancerCon, and that's a really good start with community." But, of course, there's all these different ways that patients can connect through our online chats, through other support groups, and so, I think that's a really important thing as well.

Chelsea: Yeah.

Sam: Definitely. Yeah, when speaking with patients, we often see that some feel more comfortable in certain areas. There may be an area of the three that they do without thinking about it. And in today's session, our goal was to allow participants to really reflect on the things that are working well for them. And also, be able to begin reflecting on areas that they like to build and cultivate because different than how society portrays resilience, resilience is a skill that can be cultivated. And participants were allowed to go to an area of the room that corresponds to an area they'd like to build upon and cultivate and together really thought of ways that they can build upon their resilience today and this weekend at CancerCon and then in life moving forward in the next few weeks knowing that it's an ongoing process that changes over time, and we can continue to cultivate it.

Elissa: And then something that's really going into long-term survivorship as well, right?

Sam: Certainly, yeah. One of the things that I did hear from patients is recognizing that pressure we talk about that is placed on patients with regard to resilience and what resilience may look like in survivorship. It may look a little differently than different parts of our journeys and being really thoughtful and intentional about the various ways that patients can continue to build and cultivate resilience in the survivorship stage.

Chelsea: I heard one patient share like, "Well, once I got to survivorship, a lot of the supports that I might have needed, I didn't know how to access. Right? I wasn't sure where to go or where to look for it; and there was some sharing of resources." And I said, "You know, sometimes the first step is picking up the phone or doing that search to find the resource." And I put the plug in for like, "Call Blood Cancer United." because we can help you look for that resource and find that camp or that tool you're looking for because it can be overwhelming. And I think that's what I loved this. It's like all the information sharing that was being done for folks.

Elissa: Yeah, that's really important with our Information Resource Center, as well as our partners in the young adult cancer community, like Stupid Cancer that puts on this conference and a bunch of others. And we'll have those in the show notes for our listeners today.

But you can really find so many different resources available; and you can just find those resources so much easier and not feel so lost throughout this entire process, wherever you are from diagnosis through long-term survivorship.

So, our final question today, "Why do each of you feel that understanding resilience is important for cancer patients and survivors as well as caregivers? And what is some final advice you'd like to give to our listeners today regarding resilience after a cancer diagnosis?"

Chelsea: I think it's not only understanding it, but it's shifting the way we think about it. I think like Sam said, when we think of resilience, we don't all have really positive feelings about it. And so, it was hoping to shape and shift that so that it feels like the thing folks want to move into and engage with and understand.

Sam: Yeah, 100%. I think, Chelsea and I had quite the process really exploring what resilience really means and learning about it during this process. And one of the things that I've learned is that resilience is often a term that is used to describe patients. It's not something that they get to decide upon. Cancer is not something that someone decides to have. It's given. It's forced upon people.

And while we were talking about resilience today, our goal was really to take that power back when we think of defining resilience and thinking about what is strength, what does resolve specifically look like for you? That can look so different to other people and be able to see it as a core skill that can be cultivated and grown with time.

Elissa: And then any final advice for patients and caregivers?

Chelsea: The thing that I think about is just this idea of if you're walking away with something, to know that everyone is moving through their own hard; and resilience goes along with that. And everyone's resilience is going to be different and unique to them; and there's not a right or wrong. And any step is a good step.

Sam: Yeah, if anything, I would encourage folks, whether it be resilience or other terms that fit for them, to be mindful and intentional around what's working for them. One of the things that we said at the end of our presentation today was, perhaps, taking some time at the end of each day to think about what parts of your resilience resources are you building and strengthening? What's working for you? What's an area you just fell flat on your face on? And all of that is okay and just creating space to continue to build, to learn, and to grow. And knowing that is something that will never be fully fixed. This idea of being a resilient person or a non-resilient person is bogus. It's a process, and it's something that, folks, we can begin to start talking about a little differently.

<u>Elissa</u>: Yeah, it all comes back to giving yourself grace, right? Throughout the whole process.

<u>Sam</u>: Exactly.

<u>Elissa</u>: Yes.

Well, thank you both so very much for joining us for the podcast and telling us all about this incredible session that you just did. I think I learned a lot. I believe that the people that I was surrounded with were learning a lot and really kind of thinking about these things. So, I hope that our listeners today can learn more about resilience and think about it.

And in the show notes, we will actually have a link to a podcast that we did with Dr. Rosenberg, so you can learn even more about resilience, if you'd like to take a listen to that. That will, again, be in the show notes. But, again, thank you both so very much for joining us; and I hope you have a great time at the rest of CancerCon.

<u>Sam</u>: Thanks so much.

<u>Chelsea</u>: Thank you. Thanks so much.

Elissa: And thank you to everyone listening today. *The Bloodline with Blood Cancer United* is one part of our mission 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 Blood Cancer United staff, please email, TheBloodline@bloodcancerunited.org. We hope this podcast helped you today. Stay tuned for more information on the resources that Blood Cancer United 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? Blood Cancer United 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 BloodCancerUnited.org/PatientSupport. You can find more resources for young adults with cancer at BloodCancerUnited.org/YoungAdults. These links and more will be found in the show notes or at TheBloodline.org.

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