

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Survivor Guilt: Common Yet Under-Discussed'

Description:

Survivor's guilt is not an unusual reaction among those who have experienced a traumatic event, especially those impacted by cancer. Join in as Shona sits down with Micheline Toussaint onsite at CancerCon 2019. CancerCon is an annual conference held every year by Stupid Cancer, an organization that provides support to young adult cancer survivors. Micheline is an Oncology Therapist at Inova Dwight and Martha Schar Cancer Institute in Fairfax, VA. On this episode, Micheline defines survivor guilt, how it differs from person to person and the impact it has on an individual and their loved ones. She also shares coping mechanisms that she uses to treat patients as well as helpful resources available to those who may be experiencing survivor guilt.

Transcript:

Shona: Welcome to The Bloodline with LLS. I'm Shona. Thank you so much for joining us today. I am on-site today right now recording at CancerCon, taking place this weekend in Denver, Colorado. And here with me is Micheline Toussaint, an oncology therapist in Fairfax, VA. Micheline, thank you so much for joining us today.

Micheline: Thank you and thank you for getting my name perfectly pronounced. I appreciate it.

Shona: I completely understand. People have problems with my name, as well, so I completely understand. So, we're here at CancerCon right now and, for those who don't know, CancerCon is an event held every year by Stupid Cancer, which is an organization that provides support to young adults who are currently diagnosed with cancer or who are cancer survivors. Micheline, why do you believe that CancerCon is such an incredible experience for these young adult cancer survivors?

Micheline: Oh, it really is. Every year I come here and I just watch these attendees make connections and I've watched the first-time attendees; maybe for the first time ever, realizing, "wow, there's a lot of other people me." It's just so inspiring and powerful to watch. I mean, you know, they get all kinds of education in their great workshops here every year, but I think, for me, what I watch happening is just the power of them making connections to somebody else, like me, going through this.

Shona: Exactly; exactly. So, could you tell us a little bit more about your background and what brought you to your profession?

Micheline: Yeah. I come to this as a trauma therapist. That was my first training, and then it's sort of a circuitous route how I ended up with oncology, which is my real love now, but you know, it's an interesting question to be asked. I think I've always had an interest in the human condition like what makes people keep going during difficult times. I was raised overseas as a foreign service kid in countries where there really was tremendous hardship. I saw, you know, poverty, lack of healthcare, refugees having to relocate; and I just watched people over and over again just keep going and I think, even back then, I searched being really curious what about human beings keeps them going through the most difficult times? So, I think, you know, it's not surprising to my family and people that have known me that I grew up at to become a therapist; and that's very much how I approach my work is how do I support people's resilience that's already there and just fascinated by that quality. I am trained as a trauma therapist and I really do look at cancer through the lens of trauma.

Shona: It is a trauma.

Micheline: I think it is a trauma that people have experienced.

Shona: Hmm; hmm. And the longer that I work at LLS, the more I realize that that's 100% true.

Micheline: Yeah; yeah. It's very much so. I think my first experience with the topic we are talking about today, in terms of survival guilt, is I had a very close friend in high school whose mother was diagnosed with cancer and whose disease progressed very quickly; and she died very quickly. And I didn't quite know what to say to her and anything; and it was sort of awkward at that age. And, not long after, my own mother was diagnosed with cancer and she did the same kind of cancer, and she did quite well with her treatment and she went on to live another 20 plus years. And I just always felt sort of strange about that. Like, why did I still get to have a mother and she didn't?

Shona: Right.

Micheline: And I didn't handle it well and I think it sort of made me feel awkward around my friend and we ended up drifting apart. So, I, you know, think that was my first real experience of you know, why do some people do well and some people not, and how uncomfortable that is.

Shona: Right; right. So, as Micheline just described, our topic for today is survivor's guilt and survivor's guilt includes a sense of self-blame, responsibility and sadness but often affects those who survive the trauma when others did not. It typically involves conflicting feelings. So, you are happy to be alive, but you are also experiencing grief and guilt about another's death, that can make you feel very confused...

Micheline: Right; right.

Shona: ...or distressed.

Micheline: Yeah; yeah. It's interesting that term survivor's guilt, sort of, really came into common usage during—roughly in the 1960's as a result of watching holocaust survivors and the aftermath of that so there was, you know, a significant percentages of people that had survived the holocaust of these atrocities, and 20 years later, were still not thriving—just could not leave that behind and so they, you know, psychologists were, sort of, really curious, "what's going on here" and that the term "survivor's guilt" sort of came into common usage then.

Shona: Right.

Micheline: We hear about it more, probably, in veterans and veterans of war now, also. It's a little late coming into the cancer community actually, which I'm not sure why because it's certainly—it's prevalent here, but you know, we hear about it more in other settings.

Shona: So, if this can affect anybody, really, anyone who's been through this type of traumatic situation...

Micheline: Yeah.

Shona: ...Who might be vulnerable to experiencing survivor's guilt?

Micheline: Within the cancer community...

Shona: Right.

Micheline: ...so, it is really is considered a symptom of PTSD. What's unique in the cancer community is it's broader than just the patient themselves. Certainly, patients themselves are, you know, at risk for feeling this and for a variety of reasons, not only, you know, "I survived and somebody I was in treatment with didn't". That's a common one, but also, "I didn't have as hard a time in my treatment." I hear this all the time, you know, "I only did surgery. I didn't have radiation and chemotherapy." People feel that they are feeling that they had an "easier" time with cancer, so a lot of

comparisons. Somebody feeling that they responded better to treatment might feel guilty about that.

The other big one that I hear, and it always surprises me that it's very prevalent is people feeling that now that they've survived, there is some guilt that "I am not living my best life. I'm not the poster child for cancer. I'm not organizing walks. I'm not raising money. I'm not"—this is a huge one. It comes up over and over again and I think people carry a tremendous burden of guilt over that; like it's not enough to just, you know, just live.

Shona: Not enough to survive, right?

Micheline: Yeah; yeah.

Shona: It's almost as if they were expecting, or feel that they are expected, to find a higher purpose...

Micheline: Yes; yes.

Shona: ...in their diagnosis ...

Micheline: Yes; yes and, you know, some people do find meaning in that and that's wonderful, but if that's not your thing, it's amazing to me how often that becomes a huge burden, like "I should be doing more. I should be doing more" and...

Shona: That's extremely interesting to think about it in those terms. We had a blood cancer session this morning at CancerCon; and we had a therapist speak about the psychosocial effects of a cancer diagnosis and she also brought up survivor skills.

Micheline: Yeah.

Shona: And one of the things I found so interesting when she was talking about that there's such a thing as healthy guilt. So, let's say you've engaged in a behavior that doesn't quite align with your values and you feel a little bad about it, that's actually good. It can help you realign and...

Micheline: Absolutely.

Shona: ...kind of course correct a little bit...

Micheline: Yeah; yeah.

Shona: ...but there is nothing. When you have survived cancer, you've done nothing wrong.

Micheline: Right; yeah. And that's what's confusing about it. It's not rational.

Shona: Right.

Micheline: And you're absolutely right. It's a healthy guilt. It does help us correct courses or, you know, I hurt somebody and I can make reparations. That is a useful kind of guilt. Survivor's guilt, sometimes in the literature, it's referred to as 'imaginal guilt', which I don't love because that sort of minimizes it a little bit because it feels very real to people, but it is a confusing form of guilt because there's nothing you've done wrong. I mean, all people have done is done what, as human beings were programmed to do, which is to survive.

Shona: Live, right? Right.

Micheline: That's our core energy is to try to survive and that's all they've done. Yes; so, it is. It's not a rational thing and that's what's maybe difficult to get your arms around, sort of, because it's not rational.

Shona: Are there rational aspects to it? So, perhaps, you know, I'm feeling guilty because, you know, my Mom had to take some time off from work to be my caregiver; or is that a different category than survivor guilt?

Micheline: That is included in survivor guilt actually. And that's another common one. I'm glad you brought that up. That's another common one I hear is that the guilt at much I've inflicted on my family. That, in my experience, that comes up a lot with adult survivors of childhood cancers, who often feel terribly guilty about the impact on their siblings or, you know, their parent's financial situations. And, actually, I'm working with a young woman now who was in and out of hospitals from the age of 3 to 13. So, she has really suffered and struggled; and she is a graduating senior this year and heading off to college. And, yeah, she's done really well, but she carries this enormous, enormous guilt about, you know, what her younger siblings had to go through and, you know, my Dad could retire if I hadn't cost us so much money. And, you know, it's all self-generated. When I met with the other family members, they're not feeling that. They're just all thrilled that she's going off to college...

Shona: Right; right.

Micheline: ...so, it's completely self-generated.

Shona: I've seen similar things. Working at LLS, I've, you know, talked to adult survivors of childhood blood cancers who still are experiencing PTSD and you said that survivor guilt is a symptom of PTSD.

Micheline: Yeah.

Shona: And, you know, would you say that this is the secret burden of cancer survivorship?

Micheline: I mean it is a secret burden in that it's under-talked about and it's not necessarily expected. I think people expect when somebody gets through cancer treatment and is doing okay that, "yeah; everybody, let's be thrilled" and how complicated is that "let's all be happy." So, I think this is unexpected. I think it's, often, I also think that people that carry this, don't feel they can share it with friends and families or, when they do, friends and families, sort of, shut it down. "Oh, don't feel that. Don't feel that. Don't feel that." So, they, you know, and one of the things that we talk about a lot is actually really important to give it space to be talked over.

Shona: Hmm; hmm.

Micheline: So, you know, learning to name it for what it is and be given space to talk about it is really important.

Shona: It's almost as if the rational side of the brain recognizes that this feeling is irrational and, therefore, they might...

Micheline: Yes.

Shona: ...not want...

Micheline: Yes; yes.

Shona: ... to give it that space.

Micheline: Yes; yes. And, you know, loved ones don't want to see you struggle so, you know, "just don't feel that. Don't feel that."

Shona: Right; right.

Micheline: It's a common response that isn't particular helpful, but well intended, but not particularly helpful, so...

Shona: So, what are some coping mechanisms or some ways to overcome survivor guilt or what are some methodologies that you use to treat patients who are experiencing this?

Micheline: Yeah, I mean, I think the first really important one is to name it. “Oh, that’s what this is. It’s a real thing; others feel it. I’m not crazy.” To name it, and kind of normalize it; recognize other people also have it. People really struggle. I like to educate people that this is a symptom of PTSD. It’s real. Again, it’s not rational, but it’s real. You know, the suffering from it is real. Also, to help people recognize that underneath that, very often survival guilt is a cover for deeper feelings that somebody doesn’t want to feel. So, it might be feelings of sadness, tremendous grief, anger, helplessness, and sort of helping them understand that—that it really, sort of, covers a bunch of other feelings that have to be moved through.

Shona: We are also, interested to know is there any interesting research currently on survivor guilt?

Micheline: Yeah; not a lot that I am aware of. I came across a study done by the Lung Cancer Alliance and ASCO in 2017. There may be other researches being done right now. I have not come across a lot, actually, not specific to cancer. There’s research in, you know, with veterans and other communities, but I am not coming across a lot with cancer. So, I think we are really just beginning to explore this.

Shona: Wow. Just starting to kind of...

Micheline: Bring it out of the shadows.

Shona: ...bring it out of the shadows.

Micheline: Yeah; long overdue.

Shona: It’s very long overdue.

Micheline: Yeah.

Shona: Like you said, this has—I mean, I’ve seen adult survivors of childhood cancer so they have been dealing with this for decades, right?

Micheline: Yes; yes.

Shona: Do you think that there’s an association, perhaps, between survivor guilt and other burdens in survivorship?

Micheline: Yeah; I think it can delay, people getting through sort of the feelings that we talked about. I think, often when one has survived and others haven't, there is a grieving that, you know, hanging on to survivor's guilt delays that. I think also part of survivor's guilt is sort touching onto the fragility of human life and that's a tough thing to think about. I think, you know, because, part of it also is, sort of, getting into some of the bigger existential questions, like why does one person live and one person not?

Shona: Why me; why not me, right?

Micheline: Why me; why not me. Yeah; those are the big unanswerable questions that.

Shona: And it directly conflicts, you know, confronting the fragility of life directly conflicts with what a lot of young adults—their default mindset might be right to be—to feel invincible, you know...

Micheline: Absolutely; absolutely.

Shona: ... you're confronting something that you are not really supposed to confront at this time in your life. There's a disconnect.

Micheline: Yes; yes. It's an odd thing to be thinking about life's fragility in your teens, twenties, you know. You're supposed to feel invincible, absolutely. Yeah; yeah, but I, you know, I do think some of these unanswerable existential questions why, why me, why not me, they are just difficult and it's difficult for people to be given space to explore those things. We, as humans, don't like not knowing...

Shona: Hmm; hmm.

Micheline: ...and the truth is there's still so much about the cancer experience that we just don't know. You know, you just don't know and the human brain doesn't like not knowing.

Shona: Right. And it's different for every patient as well.

Micheline: Absolutely; absolutely.

Shona: Everyone's journey is unique.

Micheline: Yup; yup; and you know, no one signed up for this. No one said, "yeah, I'd like to, carry this tremendous survivor's guilt. You know, it's just—it's inflicted.

Shona: Do you think there are other topics that aren't being addressed enough, you know, pertaining to survivor guilt that you would like to shed light on for this podcast?

Micheline: Well, I think just some of the feelings that I've mentioned. I do think, how does somebody hold both feeling a sense of power in moving forward, at the same time, recognizing the sense of powerlessness over how other people do. So, it's—we're really asking people to hold 2 conflicting things at the same time, and that's hard stuff. My own personal bias is that people sort of need space whether it's a therapist or a group, a facilitated group, that is impartial; not their families and friends because I think this is—it's hard for people that are too close to allow somebody the space and the bandwidth to explore some of these difficult feelings.

Shona: Exactly; and as you mentioned before, the friends and family are likely to say, "oh, don't feel that way".

Micheline: Yeah!

Shona: Whereas as the impartial, you know, the therapist might say, "no, you absolutely have permission to feel this way".

Micheline: Yeah; yeah.

Shona: And then you can, kind of, start to work it through.

Micheline: Yeah; yeah. I do think it's important to have space for somebody to feel the sadness about, you know, peers that didn't make it. I'm sure that's happening at this conference this year. I imagine there are people that didn't, come back this year and other people are finding that out for the first time, and I think it's important to give space to that at the same time celebrating their own moving forward. So, it's, kind of, holding both of those at the same time, which is hard.

Shona: Absolutely. So, at LLS, we are all about the resources. So, could you recommend any particular support resources for those who are experiencing survivor guilt?

Micheline: Yeah; I mean, I'm always a fan of just finding what's local. If you have a—if there's a local support group, if there's a local therapist that either is connected with a cancer center or specializes in working with cancer patients, I think that's probably the best. Or, actually, even in sort of rural areas, where there might not be access to oncology therapists, any therapist that's trained in trauma work, I think, could help somebody through survivor's guilt. I'm also a big fan of people using creative expression as a way to work through difficult feelings. So, you know, writing,

drawing, movement, art, just, you know, getting out some of those feelings that sometimes it's difficult to find words for.

Shona: Exactly. It's so interesting that you mentioned that. The reason I know about this one young adult story about surviving childhood cancer and feeling survivor guilt and PTSD from that experience is because I consulted in an expressive writing workshop. It was conducted all online at LLS...

Micheline: Yeah; yeah.

Shona: ...and, you know, they would share their writing and then they would talk about how that expressive writing made them feel. And it was so therapeutic for them.

Micheline: Oh, absolutely.

Shona: You know, so therapeutic. And I hadn't had much exposure to expressive writing before so I didn't know what to expect from the patients and it was, you know, it was as if the clouds parted and they could, like, see...

Micheline: Yup.

Shona: ...clearly again just from the exercise of getting out, you know, what was inside...

Micheline: Yes; yes.

Shona: ...this whole time. It was absolutely amazing to see.

Micheline: And there is your homework—to do another one like that specific to survivor's guilt.

Shona: That's actually a great idea. That's a great idea.

Micheline: Yeah; yeah. I and a colleague are doing a talk on this tomorrow and, as part of our talk, we're having people do a, sort of, self-reflective writing piece because I do think that's an important part of it is getting in touch with these other feelings that are underneath because if you stay with just the survival guilt, it doesn't go anywhere. It's just sort of unmovable at really getting at some of the other things are underneath.

Shona: And you don't have to be a writer or an artist...

Micheline: No; no.

Shona: ...to benefit from these. You know, people were hesitant to sign up for the program saying, "oh, I don't--I'm not a writer. I can't write." No; you're good.

Micheline: Absolutely.

Shona: Just follow the instructions and it just comes out, you know.

Micheline: Yes; because it is not about the product. It's just giving expression to something inside of you that's been bottled up that is wanting to be expressed.

Shona: Exactly.

Micheline: So, I am a big fan of the creative ways of doing it. I'm so thrilled. Thanks for doing that at LLS. That's fantastic.

Shona: Is there anything else you would like to leave us with. Any other pearls of wisdom perhaps

Micheline: Yeah; the other thing I am increasingly talking to people about is developing a practice of self-compassion. And I am really interested in following the work of Kristin Neff, who is a top researcher in self-compassion, and it is such a difficult thing for people to feel compassion for themselves. They can feel it for everybody else, but it seems very difficult for us to apply it to ourselves, but I, increasingly, am seeing how much people suffer from carrying this burden of survival guilt. And to be able to just find a way to feel compassion for the suffering that they are going through, I think is really important. So, again, I would encourage people to look up some of the stuff on self-compassion. There is a lot coming out about it now. The other tool I offer people is a gratitude practice that, you know, people have been hearing about that for years now. Just finding a couple of things every day to feel grateful for. It's a little tricky with the gratitude practice because I've had some people also turn that into another reason to feel guilty. "Oh, I'm not grateful enough." You know, and that can be a flip on it so—but I think that could be another way to sort of off-set the guilt is to find something in my life today that I am grateful for. , at some point, you know, I do think it's when somebody wants to, sort of, unburden themselves, it's almost like a decision that they have to make. You know like, "I am just so tired of carrying around this, you know, burden my whole life. I'm just ready to lay it down. I may not feel that I deserve to yet or"—you know what I mean; sometimes it, sort of, doing it before rationally you have argued your way into that. At some point, I think it's a decision you make like, "I've carried this long enough. It's not helping me. It's not helping anybody else." I think once people make that connection, it's not helping anybody else for you to be burdened with this. You know, if you weren't—one of the questions I often ask people is, "if you weren't carrying this heavy load, what might else—what would your life look like"?

Shona: Wow.

Micheline: You know, what could you imagine your life like if you put—lay down this heavy, heavy burden? And just to get people thinking about that.

Shona: That's so interesting that you refer to it as a decision that...

Micheline: Yeah; yeah.

Shona: ... you know, that they can make to just let it go.

Micheline: Yeah; yeah. Not an easy decision...

Shona: Of course.

Micheline: ...but I think it starts with just a decision, like, "I have carried this long enough. It is not serving me. It's not serving anyone else. I'm just going to lay it down." Not just. It's not that simple, but that is sort of the decision part of it.

Shona: That is so fascinating and so useful, I'm sure, for our listeners. To wrap up this podcast, like I said, LLS is all about the resources. So, I need to share with our listeners some of our resources, specifically for young adults and for all of our listeners as well. We have educational publications that are free and downloadable from our website. And we also have online chats, which are moderated by an oncology social worker. So, you can join a chat based on your diagnosis or we have a chat for young adults as well. Similarly, we have an online patient support forum called LLS Community, which kind of functions like a Facebook-esque social media platform, where you can create an account, and just talk to other people, who, you know, have been through what you're going through or, you know, a completely different diagnosis to, you know, get a different perspective. And, you know, you can join groups, again, with your diagnosis or with a young adult group. If you're interested in fitness, we have one for that as well. So, it's a great tool to connect with people from all over the world, really. We have patients from all over the world on the LLS Community. We also have the Patti Robinson Kaufmann First Connection Program where you will be matched with, a survivor who has been through pretty much what you've gone through. So, you will be matched for age, and diagnosis and they can kind of walk you through what to expect when you are, experiencing this diagnosis. And then, finally, we have the Information Resource Center. Our information specialists are available to answer kind of the trickier questions—maybe financial. You have questions about finances and they can provide financial aid and connect you to other educational resources and programs.

So, we offer so many resources. We encourage all of our patients to take a look. They're all available on our website www.lls.org. So, check those out today. Thank you so much for joining me on this episode. I know I learned a lot just by talking to you. This has been great and I know that our listeners are going to learn a lot as well.

Micheline: I do feel that I could put in one more pitch just for the organization that is sponsoring this conference for Stupid Cancer.

Shona: Absolutely.

Micheline: They have a lot of stuff so...

Shona: They do. They have a lot.

Micheline: ...online just go to Stupid Cancer and they have online support groups and chats and similar, but LLS does a tremendous amount for the cancer community.

Shona: Well, thank you.

Micheline: Thank you, LLS.

Shona: Thank you. Well, if that's all. Thank you again for being on this episode and it was wonderful talking to you.

Micheline: Likewise.