

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'LIVE! At CancerCon: Coping with Cancer'

Description:

Please join us for this second live episode from CancerCon® 2023, a young adult cancer conference presented by Stupid Cancer®. In this episode, we'll be speaking with experts who discussed "chemo brain", palliative care, and healing through writing.

Cancer patients and survivors of all ages, whether newly diagnosed, in treatment or post-treatment, can benefit from hearing from these experts.

Be sure to tune into the previous episode from CancerCon, where we heard from young adult cancer patients and survivors on the milestones and challenges that they have experienced along the road of survivorship.

Transcript:

Elissa: Welcome to *The Bloodline with LLS*. My name is Elissa, and today we are podcasting live from CancerCon®, a young adult cancer conference put on by Stupid Cancer®. This year the conference is taking place in Atlanta, Georgia, and is attended by several hundred young adult cancer patients, survivors, caregivers, and nonprofit and healthcare professionals. LLS 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.

The LLS theme at this year's conference is the Roadmap of Survivorship. The term survivorship is defined by the National Cancer Institute as the health and well-being of a person with cancer from the time of diagnosis until the end of life. This includes the physical, mental, emotional, social, and financial effects of cancer that begin at diagnosis and continue through treatment and beyond. The Road of Survivorship has many stops and detours along the way, and there are sessions at CancerCon that can



address the issues that may come up for patients and survivors and how to cope with them.

In the last episode, we interviewed blood cancer patients and survivors on where they are along the road of survivorship. Today, we want to hear from the presenters at CancerCon about the highlights of their presentations on the unique issues that affect young adults with cancer. So let's get started.

Aerial Donovan: My name is Aerial Donovan. I am the Chief Program Officer and Cofounder at Cactus Cancer Society. I was a caregiver for my dad who had AML and I'm also a survivor.

Elissa: So you did a workshop today. What was the name of your workshop and why do you feel like it's important to have at CancerCon?

Aerial: The name of the workshop was "Oodles of Thoughts". It's a doodle journal workshop and I just really resonate with the idea of using my creativity to focus my thoughts and energy when it comes to processing things. And having been a long-time CancerCon attendee, I just thought it would be a great addition to their already awesome lineup.

Elissa: That's great. I just sat in your workshop, and it was tons of fun. Could you tell our listeners what we did in there?

Aerial: Yeah. So, the process is looking at a prompt, which could be a picture or a poem or a sentence and giving the participants usually 7 to 10 minutes to respond whatever comes to mind first. Sometimes it's senses related or just whatever resonates with them on the page. They respond to it via doodle or writing anything that comes to mind and then we process it together as a group and they get feedback from their peers.

Elissa: Why is this type of writing or doodling beneficial for a cancer patient?

Aerial: All of our programs, they're peer-to-peer based, so I mean, who doesn't like to hear from someone who's been in their shoes that they feel similarly or that something resonated with them, or they understood where they were coming from? And I think that's part of what makes Cactus Cancer Society so special is that that's pretty much what all of our programs are based on and just always nice to know you're not alone in the room.

Elissa: Yeah. I thought it was just really neat. What happened was you put up these prompts but were pictures. So, we looked at the pictures and then just wrote about it or doodled about it. And then, having that bit of feedback from our peers as well, that seemed to provide connection as we discussed what each of us wrote and how we saw things the same or maybe we saw things a little bit differently. And so, I thought it was really neat that it provided that sense of connection as well.

Aerial: Yeah. One of my favorite parts of this program is just seeing where everyone's train of thought leads them. It's so unpredictable but also always relatable and it's just really neat to see a community come together.

Elissa: Absolutely. So, our final question today. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." So based on your professional experience and experience as a cancer survivor yourself, what would you say to current patients and those who have completed treatment to give them hope after a diagnosis of cancer?

Aerial: Wow, that's a tough one. Something that my husband and I used to remind each other of when we had particularly hard days, even when my dad was sick, was that we're going to take it one day at a time, and we're not going to look too far forward, and we're not going to think about the situation necessarily and how bad it is, but just taking it piece by piece. And that was enough to give us hope for tomorrow. Tomorrow didn't seem as far away as like six months from now or a year from now and that was enough to help carry that hope forward.

Elissa: I love that. And that makes me think of your last prompt for the day as well which was "Small steps are-"

Aerial: Are still progress.

Elissa: "-are still progress."

Aerial: Yeah.

Elissa: And that was just really neat. And that kind of says that is that you just keep pushing forward, right?

Aerial: Right.

Elissa: Awesome. Well, thank you so much, Aerial, for joining us today and telling us all about this really cool workshop.

Aerial: Thanks.

Alique Topalian: Hi, my name is Alique Topalian. I have my PhD in Health Promotion Education and my Masters of Public Health. I work in survivorship and supportive services as a researcher at a large cancer center, and I myself am a two-time acute myeloid leukemia (AML) survivor. I was first diagnosed in 1998 at age 4 and then I became the first ever person to relapse after 22 years in 2021 at age 27.

Elissa: So, what was the name of your session and why was it important for you to present on this subject?

Alique: The name of my session was "Cancer-Related Cognitive Impairment: Strategies and Support for Chemo Brain". This is a really important topic because it affects about 70% or more of cancer survivors during treatment and about 35% of survivors months to years beyond active treatment. We see this a lot in all age ranges, but a lot of times with the AYA population, we actually see the concerns about their cognitive impairment minimized. Being told that it will get better over time, that

they're young, their brain will bounce back. Those typical things that AYAs hear a lot, about their concerns.

Elissa: So, what I noticed after sitting in your presentation was that it was definitely not just about cognitive impairment. Could you tell us a little bit more about your presentation and some highlights of what you covered?

Alique: Yes, of course. I know it can be a little bit confusing because my title does have chemo brain in it, but chemo brain is actually so much more than related to chemo. Cancer-related cognitive impairment is a whole array of symptoms that can happen because of cancer or any of its related treatments – surgery, radiation, immunotherapy, chemotherapy, hormonal therapy. Anything that can treat cancer can actually result in cancer-related cognitive impairment. If you just say, "chemo brain," that minimizes people's symptoms. They then think, "Oh, I didn't have chemotherapy, why am I having this cognitive impairment? Why am I experiencing these symptoms if I don't fit into that category?"

So, us in the field have really been trying to figure out how to restructure this naming process so it captures everything that's related to it. We can't actually tell through research right now, is this related to the cancer or is this related to the cancer's treatment? It's all together. We've seen patients who have cancer-related cognitive impairment even before starting treatment, so it could even be an effect of cancer itself.

Elissa: And what else did you cover in the presentation?

Alique: So, one of my favorite things to talk about with this is cytokines. So, cytokines are in your body. It's what happens when you're sick. It happens if you have a lot of inflammation they get released into your body. Think of, you have the flu, you're feeling really under the weather, you try to study for a test or write a paper and your brain feels foggy. It's not working to its full potential. That's because of the cytokines.

Cytokines themselves have an effect on cancer-related cognitive impairment, but it also comes from things such as cancer's treatment; hormonal changes such as premature menopause; medical problems such as genetics, pain, and medication side effects; poor sleep, depression, anxiety, and mood; chronic stress and loneliness; poor nutrition and lack of exercise.

Something to keep in mind with cancer-related cognitive impairment, this isn't necessarily something that we see where it's like ADHD where you can be prescribed a stimulant medication and it will help you focus and your symptoms will get better. We actually haven't seen an effect of many medications on cancer-related cognitive impairment. It comes down to overall behavioral strategies and different coping strategies and techniques that you can use in your everyday life that work best for you in your own learning processes.

Elissa: Okay. So that's when, when you talked about exercise and loneliness and depression, all of those things have an effect on cognitive impairment, correct?

Alique: Exactly. And it also goes into cancer-related fatigue. The more fatigue you're experiencing, the less fast your brain is going to work. Different things that can help with your fatigue overall also help with your cancer-related cognitive impairment. They all are very interrelated to one another.

Elissa: That's really interesting. So, for patients and caregivers listening, they may be able to work on all of these other things in their life. Try to find a way to exercise, work on mindfulness, relaxation techniques, things like that that would eventually help them with their cognitive impairment.

Alique: Exactly. Exercise has positive effects on fatigue and has positive effects on overall cognitive functioning.

Nutrition, it's not necessarily that there's a huge link between, eat this special diet and your cancer-related cognitive impairment's going to go away. No, it's about, using

things such as Omega-3 fatty acids that help your brain and your heart health and nutrition shown with lowering levels of fatigue which then impacts the cognitive impairment.

Depression and anxiety. A lot of times people don't think of different mood disorders and mental health conditions affecting their brain, but symptoms of both of them include issues with cognition. So, if you have underlying depression or anxiety that's untreated, that will have effects on your cognition even if that's something that you don't typically think about.

Elissa: Wow, that's really interesting.

So, our final question today, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." So, based on your professional experience, what would you say to current patients and those who have completed treatment to give them hope after a diagnosis of cancer?

Alique: I would say that it's not a "new normal", but it is life now. I've never liked the "new normal" because there is never really a normal to begin with. But we need to learn how to deal with our own life now, and we need to be adaptable and figure out what works for us now.

When you're trying to start exercise, you cannot jump in at the same level that you did before your treatment because your body's not the same as it was before treatment. You need to pace yourself, start things in smaller increments. If you, say I'm going to start exercising, an hour a day every single day, that's harder to keep up than saying, "I'm going to start off small. I'm going to start doing a 15-minute walk once a day and work myself up to it."

Same thing with nutrition and sleep habits, mindfulness. You can't just say, "I'm going to sit down. I'm going to practice 30 minutes of mindfulness." It's something that you need to work your brain up to. Practice makes perfect.



Your brain has levels of plasticity in it. That's how it keeps information that's most important. It gets rid of the information that's least important that you don't use anymore. If you continuously try practicing strategies that can help improve your cognition, that can help improve your symptoms, that will form new neural pathways in your brain.

So your brain can change, and it can grow, and it can adapt over time. It's just about making things a habit and starting small enough where you won't be discouraged if things don't always work out perfectly the first time around. Give yourself grace, take breaks, and realize life now is different. But you need to be accepting of it, and that could be really, really hard. I know that, but, it's life now.

Elissa: Well, that is wonderful advice to take small steps and keep moving forward. And so thank you so much, Alique, for speaking with us today. I thought it was a wonderful presentation, and I hope you enjoy the rest of your time at CancerCon.

Alique: Thank you so much.

Elissa: Thank you.

Robert Bennett, MD: I'm Dr. Robert Bennett. I am an AYA cancer survivorship researcher at the Mayo Clinic.

My connection with blood cancer is that this is the population that I serve both clinically as well as the population that I research to advance their care.

And I'm proud to say that my own mom is a survivor of lymphoma, 30+ years ago, and is one of my inspirations for my work.

Elissa: That's wonderful.

Peter Drahms, RN: My name is Peter Drahms. I'm a registered nurse. I have worked at the University of Rochester Medical Center helping to treat patients with

leukemias and lymphomas. On a personal note, my father has multiple myeloma, and he's currently being treated for that.

Elissa: Okay. So, what was the name of your session, and why was it important for you to present on this subject?

Dr. Bennett: The name of our session was Myth Busters: The Palliative Care Edition. And the reason it was so important for us to present on this is because palliative care is widely misunderstood, both in the patient community as well as in the provider community. And there's a lot of misinformation floating around about the purpose of palliative care. We wanted the participants at CancerCon to have a better understanding of what palliative care is, what it means, and how it could help them along their journey with cancer.

Elissa: That's great. So what were some of the highlights of your presentation?

Peter: Some of the highlights of our presentation included differentiating between palliative care and hospice care.

Elissa: Yes.

Peter: We also tried to give the participants a chance to voice what their experiences are and what their impressions of palliative care are, if they have any, and have an in-depth discussion about resources available to them and how they can best be utilized.

Dr. Bennett: Another one of the highlights is the multipurpose of palliative care, that we service spiritual and all of the psychosocial and physical needs of the patient. And we help make their lives be the best they can possibly be from all of those aspects, including managing their pain, managing any spiritual distress they may have, and even working towards getting them pet therapy, art therapy, and all of those creative therapies that help make their experience better.

Elissa: One thing I loved about your presentation was that you opened up some questions to the attendees in the room. Could you tell us a little bit about those, and the discussions that followed?

Dr. Bennett: Sure. Some of the questions we were asking related to advanced care planning, and what are things that bring some of the participants comfort, who they want present with them in the hospital or at home. We also had questions about what people would want their family and their loved ones to know about them that they might not have voiced already. And questions about spirituality and what brings people spiritual comfort. Basically, our objective was to open up a conversation about these things that they could open up with their care team and their families at home to provide the best care possible for them.

Elissa: Now, much of that was based on a booklet, correct?

Dr. Bennett: Correct.

Elissa: Can you tell us a little bit about that?

Dr. Bennett: This was based on the "Voicing My Choices™" pamphlet which was designed as a tool to facilitate conversations about goals of care and look at these different dimensions of social, physical, and emotional well-being. And it's something that patients can share with their families and even bring to the hospital and share with their care team, not as a legally binding document, but something that has their preferences noted because it'll inform their decisions moving forward and give their family and healthcare providers a snapshot of what they want their care to look like.

Elissa: Okay. So what would you say to any patients or caregivers listening about getting palliative care? How do they get it? What are the steps? Do they just talk to their healthcare team?

Peter: So, I think it's very important that people are able to self-advocate. There are many institutions throughout the country that are very proactive from a palliative care

approach, and they will come to the bedside and offer the services available through the palliative care team just like any other specialty you might find in the hospital.

However, we found that there are many other institutions that maybe aren't as familiar with palliative care or aren't as comprehensive in the delivery of palliative care; and that's where there are gaps in the delivery of that to the patients. So, it's important they understand there are other options that they could consider such as going to their primary care physician for assistance with things like nausea and pain, or there are some other online sources they could access to help address those needs.

Elissa: Is palliative care good for most patients, or is it something that you need to have a surgery, or you need to have some more aggressive treatments? Who's it good for?

Dr. Bennett: Palliative care is good for patients who are living with any form of serious illness. It's not restricted to cancer. It's not restricted to advanced cancer. It could be anything that qualifies as serious illness. If you have kidney dysfunction, pulmonary issues, anyone who is living with a serious illness, it's there to provide symptom management and psychosocial support along their journey with their illness.

Elissa: Okay. So, what would be the difference of getting palliative care versus just your treatment team giving you some medications for side effects such as nausea or pain?

Dr. Bennett: Well, the treatment team can certainly manage some of those larger side effects such as nausea and pain. However, palliative care is more geared to providing some of those complementary alternative therapies that are nonpharmacologic and can enhance the patient experience and help reduce their pain, anxiety, and suffering without always using medications to achieve that objective.

Elissa: Well, our final question today, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." So based on your professional

experience, what would you say to current patients and those who have completed treatment to give them hope after a diagnosis of cancer?

Peter: I feel that hope is extremely important, regardless of the phase of care that you're in. I think it's important to be mindful and be present, but always be hopeful and looking forward to good things to come and try to maintain some positivity.

Communication and collaboration with your team, your family, your friends is so important and that really offers the best possibility of you getting the outcome that you desire, regardless of the phase of care that you're in.

Dr. Bennett: I would say that hope can look very different in a variety of ways and that there's always something to hope for, no matter what it might be. And the patient's hopes and what their objectives are are things that we can support as a team to make their lives better.

I'd also say that hope is what provides patients purpose and a reason for going through their day-to-day treatments and continuing to persevere through these. For a lot of us who work in oncology, supporting their hope and their purpose is really what drives us and gives us personal satisfaction and professional purpose.

Elissa: That is great. Well thank you both so much, Dr. Bennett and Peter, for joining us today and for coming back to CancerCon. We're happy to see you back. I think you have some wonderful presentations that you always do and get people really engaged. We really appreciate you today talking all about palliative care that is such an important topic, so thank you.

Dr. Bennett: Thank you, Elissa.

Peter: Thank you, Elissa.



Elissa: This concludes our second episode podcasting live from CancerCon 2023. Be sure to tune in to the prior episode where we interviewed young adult patients and survivors at CancerCon to hear their thoughts on the long windy road of survivorship.

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 the 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 the 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. You can find more information on



programs for young adults at [LLS.org/YoungAdults](https://www.lls.org/YoungAdults). All of these links will be found in the show notes or at [TheBloodline.org](https://www.thebloodline.org).

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