

## THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

### ***Episode: 'LIVE! At CancerCon: Ghosts, Growth and Guidance'***

#### **Description:**

Please join us for this special episode live from CancerCon®, a young adult cancer conference presented by Stupid Cancer®.

A diagnosis of cancer can present many challenges when it comes to relationships with others and the relationship you have with yourself. In this episode, we speak with experts about rediscovering yourself after cancer, exploring mental health treatment, and cancer “ghosting”.

Be sure to tune into our prior LIVE! At CancerCon episode, where we interviewed young adult patients and survivors to hear their thoughts on transitioning from their oncologist to a primary care provider.

#### **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 Austin, Texas, and is attended by nearly 250 young adult cancer patients, survivors, caregivers, as well as 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 total attendees each year.

The LLS theme at this year's conference is Transitions in Survivorship. There could be many different types of transitions that a cancer patient may have after a diagnosis. Often, patients and survivors may be trying to find their way back to the person they



knew before cancer, or they may be dealing with relationship changes or emotional struggles that came about as a result of the diagnosis or treatment.

In the last episode, we interviewed blood cancer patients and survivors on transitioning to primary care. 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.

While we'll be discussing issues that young adults face, these are topics that are relevant to all ages. We encourage you to stay tuned and find connection as all patients and survivors of cancer transition from diagnosis through survivorship. So, let's get started.

**Ambreen Maan, MSW, LSW:** Hi, I'm Ambreen Maan. I am a licensed social worker and a Program Manager at the American Brain Tumor Association®, and I am a Hodgkin's lymphoma survivor.

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

**Ambreen:** My session was, "It's Me, Hi! Rediscovering Yourself After Cancer." It was kind of inspired by that Taylor Swift song where she talks about how she's the problem. And, really what made me want to do this session is my own experience as a survivor. I'm in that phase now of being 10+ years out where I'm trying to figure out who I am. Do I still talk about my cancer? Is that still a significant part of my life? And as I was thinking about that, I realize that's a struggle a lot of people experience from the point of diagnosis onward throughout the entire experience of who are you now that you have cancer?

So much changes after a cancer diagnosis. You're not able to do the things that you used to in the same way. A lot of people talk about the new normal, which is a phrase that I hate, and I like to talk about it instead as the new version of your previous self.



**Elissa:** I love that.

**Ambreen:** And that's really what the talk was focused about. It's being able to understand yourself, gain more self-awareness of where you're at, what you're going through, and how to own your story and become reacquainted with yourself despite your cancer.

**Elissa:** Yeah, we have a lot of listeners that may be in treatment right now, newly diagnosed, or they may be several years out of treatment. Is this something that is still affecting people that are years and years out of treatment, really kind of discovering who they are, letting go of things?

**Ambreen:** Definitely, yeah. I think it's a continuous process.

**Elissa:** Yeah.

**Ambreen:** I think it's a continuous process for anyone, regardless of if you have cancer or not, figuring out who you are as you go through life and the challenges you experience. But as a cancer survivor, it's kind of more at the forefront because you have had to go through this life-altering, life-changing experience-

**Elissa:** Right.

**Ambreen:** -where everything that you thought you knew gets thrown out the window. It's like a wrench thrown into the cogwheels of all the plans that you had. So, I do think it's a continuous process, and I think it starts from that moment that you were diagnosed, and you find out you have cancer, and it continues onward.

There's times where I feel like we have a better hold of it, a better grasp of it, but it's really this rollercoaster that I feel like we are constantly going through. And it's constantly changing as we grow, as we get older, as we may experience late effects from our treatments. I think we're constantly having to reassess who we are, where we're at, and what we want to do moving forward.

**Elissa:** Yeah. So, digging into your session a little bit, you started off with, first of all, who are you and what makes you YOU essentially, right? Can you talk a little bit about that in the little diagram that you had?

**Ambreen:** Yeah, yeah. So, I like to start a talk like this off with just talking about the multi-faceted aspect of who we are as individuals, as human beings. There's so much that goes into defining who we are. It could be our social life, our friends, our relationships, our hobbies, our interests, our careers. We are defined by our values, our beliefs, the people that we love, and the things that we love to do.

So, just understanding all those different aspects helps us to understand who we are. And when we're diagnosed with cancer, some of those things change. You know, we might not be able to hang out with our friends the same way, or we may have had to stop working or stop going to school because we're in treatment. So, all those things that made us who we are, they feel like they're out of reach. And when they feel like they're out of reach, that's when we can feel that loss of identity. Those things that we defined ourselves by, now they're not there anymore, or they're not the same way that they used to be; and I think that contributes a lot to that loss of identity and trying to figure out who you are after cancer and learning that you are more than that diagnosis and that all those different things that make you who you are, they're still there. You just have to find different ways to engage with them.

**Elissa:** Yeah, now one of the things you talked about was grief, and I really like that you talked about the seven stages of grief. I think a lot of people have heard of the five. But the seven stages had, obviously, a couple more. And then, it was kind of in a U shape as well and showed that downward trajectory but then that upward trajectory as you find yourself. Could you talk a little bit about that?

**Ambreen:** Yeah, yeah. So, I know people are used to the typical five stages of grief; and the seven stage phases model, that I like to talk about more in my work as social work, it expands on that more. So, it goes from that first phase of that shock and

denial when you first find out about a loss or something big like a cancer diagnosis. And then it goes into some of that pain and the guilt that you may experience as some of that shock starts to wear off and you start to realize what you're going through. You feel the hurt of why is this happening to me and what I'm going through. And eventually that may turn into anger where you're feeling angry at yourself that this happened, angry at the world, angry at your doctors. And when the sharpness of that anger starts to wear off, that's when depression may set in. That's when you start to realize this is real, this is happening. The sadness of what you're going through, the heaviness of it all really hits you; and I feel like that's one of the lowest points in that entire U-shape, like you described, stages of grief.

And it's the point where a lot of people tend to feel isolated, and they become withdrawn from people. But it's at that point that I always tell patients and survivors that it's when you're in that moment that you need to push yourself. You need to push yourself to turn to others, turn to the people that you love, the people that you care about, the people that you trust because they're there to support you. And the more that you isolate yourself, the more that you're keeping yourself in that depression state so you can't go forward.

And when you do start to open up and you turn to others, that's when you get to that next phase which is that upward turn where things may start feeling better because you have support, you have people to talk to. And as you start to feel better, you get to the next stage, which is the reconstructing and rebuilding stage. So now, you're feeling better, you have more energy, you can start to find ways to build yourself up again, start to engage in those activities that you like to do again, or find more creative ways to engage in them differently, if you have to.

And from there as you start to build yourself up again, eventually you get to that acceptance stage, which is where you find this deep peace about what you've gone through. You may not understand why it happened, but you can be at peace with it.

And similar to the five stages of grief, I always like to describe this as a continuous process. It can be cyclical. Some people go through all these phases. Some people only go through one or two, or they may find themselves going back and forth through it as well. But the important part about recognizing these stages and naming these stages is that it helps you to understand where you're at and normalizes what you're experiencing. And it gives you tools. You have something to look forward to, something to try to get yourself out of whatever stage that is in and into the next one.

**Elissa:** So, now that we've talked about figuring out who you are and then the stages of grief and loss and really thinking about that, then what? How do we cope? How do we move forward?

**Ambreen:** Yeah, so just understanding where you're at isn't enough. That's just the first step. The next step is to actually take action and do something about it and fill your emotional toolbox with the tools that can help you cope. Some tools that I describe in the session are connection with others; and I think that's why something like CancerCon is so important because it gives you that community. It gives you connection to people who really truly understand what you're going through. So, that's one, just connecting and being able to talk about what you're going through, expressing yourself, and understanding, recognizing your emotions, naming them, and allowing yourself to experience those emotions.

I think professional support is so important. It's something that people tend to shy away from. It can be a little nerve-wracking, and those first few sessions are difficult when you do start therapy. But it's so important because it gives you a professional that you could talk to about what you're going through; and they can help you work through some of those different emotions and find healthy ways to cope with it.

**Elissa:** So, are there any other highlights of your session or some takeaways that you want to discuss?

**Ambreen:** Yeah. I would say something that we talked about a lot, and this came up in the discussion at the end of the session too, was self-compassion. And self-compassion is so important. In the session, I described it as being your own friend, learning to treat yourself the way that you would treat your friends or the way that your friends would treat you.

In our discussion with, the attendees in the session, a lot of them talked about how that can be hard to do, that they tend to beat themselves up. And it's totally normal. We are our harshest critics. We tend to notice and focus in on all of our flaws. Like one girl mentioned, her hair growing back and her hair is different. And she's so hyper-focused on that, and we focus on these things ourselves; but chances are the people around us, they don't notice that or they wouldn't talk to us that way, the way that we talk to ourselves.

So, I would say one of the biggest takeaways that I would want people to remember from the talk is to just be kind to yourself. To recognize the way that you talk to yourself, and to change that because we tend to speak to ourselves negatively and we don't realize it often. So, I always recommend people to start keeping a list. Every time you say something negative about yourself or you think a negative thought about yourself, write it down. And that's when you realize, in one day I've said these ten different negative things about myself. And when you think about that same situation, when you think of a friend being in that situation and how you would talk to them, chances are you would be gentle with them. You would be kind to them. So, why do we think that it's okay to talk so negatively and harshly to ourselves?

And the answer is it's not okay. That part of our brain that controls our language and the words that we choose to use, it also controls our heart rate. It controls our hormone levels, our immune system. So, when we're using negative words to talk about ourselves, we're increasing our heart rate. We're stressing ourselves out. We're lowering our immune system. We're causing ourselves to feel worse by talking to ourselves in that negative way. And when we change it and we talk to ourselves in a

positive way, we're increasing our emotional resilience, our strength, and we're helping to decrease those stress levels and change that neural pathway in our brain into being one that promotes positive reactions instead.

**Elissa:** Yes. Now, that had also to do with the homework that you gave. So, let's talk about that and give that to our listeners today.

**Ambreen:** Yeah. So, the homework that I gave, and I am going to task all of the listeners to do this as well, is to think about something negative that you say to yourself. It could be a word. It could be a phrase. It could be a thought that you tend to have oftentimes, or it could be something negative that you've just been holding onto for a while. And then write that down on a piece of paper.

I tasked our conference attendees to write it down and to fold it up and keep it with them throughout the conference. And then throughout the conference, I asked them to engage in some of those self-compassion and coping strategies that we talked about in the session as they're going through different sessions, meeting people, making friends and connecting. And by the end of the conference, I asked them to find that piece of paper, wherever they put it, tear it up, flush it down the toilet, find a creative way to get rid of it and let it go.

So, I'm going to ask our listeners to take a moment to write down that negative thought, that negative phrase on a piece of paper. Keep it with you for the day, and then by the end of the day, I want you to find a way to get rid of it. You can burn it. You can flush it down the toilet, tear it up, whatever you want. I want you to get rid of it and make the intention that you're letting this go, and you're moving forward from this.

**Elissa:** Yes, I love that. That's perfect. Now our final question today. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your professional and personal experience, what would you say to current patients





and those who have completed treatment to give them hope after a diagnosis of cancer?

**Ambreen:** Ooh, that is such a good question. I think the most important thing to remember is that you're not alone. And I think that does give a lot of hope, is reminding ourselves that we are not in this on our own. Sometimes it feels like it. Sometimes it feels like we're the only one that's going through this, but there's a whole community of people who are in your shoes, who are experiencing the same thing.

And we all struggle. We all have terrible days, bad days. But that's just a day. And the next day may be better, and it can get better, and reminding ourselves that we're not alone in this, I think, is the most important and to reach out and to connect with other people, I think, can really create that sense of hope because you have that community that gets what you're going through.

**Elissa:** Absolutely. And that is just what we're doing here at CancerCon, building community and meeting other people who've gone through just the same thing. Even if it's a different cancer, it kind of seems like we've all just gone through a lot of the same things; and we can all relate to your session today and finding yourself after diagnosis, after treatment, after you move on to the new version of your previous self. And so, we really appreciate you joining us today, Ambreen. And I hope you enjoy the rest of CancerCon.

**Ambreen:** Thank you. You too, and to everybody listening, don't forget to do your homework.

**Elissa:** Yes, absolutely. All right, thanks so much.

**Ambreen:** Thank you.

**Megan Gilman, MD:** I'm Dr. Megan Gilman. I'm a psychiatrist currently at Duke Cancer Institute. My connection is my father's actually an oncologist, and my uncle is

a pediatric oncologist. And it just sort of was this theme throughout my life. So, I feel connected to it in a way like it's meant to be that I'm doing what I'm doing.

**Elissa:** So, that drew you more to the psycho-oncology space?

**Dr. Gilman:** Yeah. I love psychiatry and I think when I discovered psycho-oncology, it just felt like exactly why I had gone to med school to end up doing this work.

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

**Dr. Gilman:** So, the name of my session is, "How Psychiatry Can Help You Cope." I really wanted to present to this audience in particular, destigmatizing and demystifying psychiatry. I think that there's been such an emphasis on mental healthcare in recent years, which is amazing, and people are much more willing to pursue therapeutic supports and group supports and be more open with peers and even with providers. But I still think that psychiatry has always been this last resort for mental health. Whereas I really see myself in the oncology sphere as a psychiatrist in oncology as a member of the team. I am someone else you can have on your team who can address things from a different direction.

And I want people to feel comfortable and good about a referral to psychiatry rather than it feeling like some sort of, "Oh no. We don't really know what to do with you now." So, that was my goal is this is how I do what I do, why I do what I do, and the intention is really just to be an additional team member who's able to sort of address things from a different direction.

**Elissa:** Okay, it sounds like it would be a good thing to have on your treatment team, somebody who could really help with the mental health aspect of a cancer diagnosis.

**Dr. Gilman:** Right and help both therapeutically and with support and things like that. But, if the symptoms are really troublesome and really getting in the way of progress, of quality of life, of tolerating treatment, all the things, why not explore the

options for helping with that? Again, I think psychiatry in oncology is really designed to be additional help.

**Elissa:** Yeah. So, just to define terms for our listeners who may not know, what is the difference between psychology and psychiatry?

**Dr. Gilman:** So, in psycho-oncology, there are both people from psychology backgrounds and psychiatry backgrounds. So, psychology is an academic and clinical training. Very skilled therapists, and very skilled researchers. Psychiatry is actually a medical specialty. So, you go to medical school and when some people choose neurosurgery and some people choose hematology-oncology, some people choose psychiatry to go do their residency in. And so, it's actually a medical specialty with a residency and then subsequently possibly a fellowship in additional training and additional specialization. And so, I have an MD or some people have a DO, but that means that we can prescribe medication. We also have training in therapy in all of the stuff that comes with addressing mental health.

**Elissa:** And speaking of medication, you did say that not everybody that sees you goes on medication, correct?

**Dr. Gilman:** Absolutely. I really think that medication can be helpful for very specific things, and when someone is describing to me that specific thing that medication can help with, I'm going to encourage it because I can help. But, there are plenty of times that patients are struggling with things that I don't have a medication for. And I will tell them that, and we will access all the other supports at that point, whether that's therapy with me, additional therapy with a psychotherapist or a social worker, whether that's a group therapy – all the different supports available but not medication, unless there's a specific reason that I think that can be helpful.

**Elissa:** And in what situations would a cancer patient be needing to be referred over to a psychiatrist?

**Dr. Gilman:** That's a really good question. It's a very broad range of things. But basically, when patients are struggling to cope, often they'll get referred to psychiatry. They could also have been referred first to psychology. Sometimes it's the therapist that says, "I'd like you to see psychiatry about medication" after they've been working with a patient for some time.

But then, we also get referrals from oncologists for things like treatment side effects. A patient who has mood symptoms from Tamoxifen or from steroids and needs help managing those side effects. So really, my role is supporting the oncology teams. Whatever they need to get this patient through this process and ideally back to where they want to be on the other side of everything, then I am there to support that.

**Elissa:** Yes. And you discussed in the session that you really want to dispel a lot of myths about psychiatry. What kind of myths were you working to dispel?

**Dr. Gilman:** That a psychiatrist is going to force medication on you. I hear that a lot. That the assumption is seeing a psychiatrist means you are going to be put on a medication. And I don't like to think of putting my patients on medication. I have discussions with my patients, and I can make recommendations, and we can decide things together. But I think that's an important distinction.

One of the things that I mentioned in my talk is trying to find the right psychiatric medication is a lot of trial and error sometimes. And, I think sometimes people feel like guinea pigs, like the psychiatrist is just, "Try this, try that, try this, try that." But, really there's a process there and the goal is ultimately just to be helpful. And it does take sometimes different attempts at different medications to know how an individual is actually going to respond to something.

**Elissa:** That's almost not much different than when we're talking about other medications for cancer, really individualized medicine. With psychiatric medicine, having to really find that perfect fit for that person, right?

**Dr. Gilman:** Yeah, exactly. And there's a lot of anecdotal evidence in addition to what it says on the package of the medication that goes into choosing for this person at this moment, based on what a patient wants from a medication. How I can meet their needs in the best way with a medication. And that takes some time to get to know the patient, obviously, and get to know their goals but also sometimes just to try different things.

**Elissa:** Another thing that you mentioned was with supportive therapy in oncology, you had specific goals for patients. Could you talk about that?

**Dr. Gilman:** Yeah, so I think the supportive therapy with cancer patients is really directed at helping move this patient through the entire experience. Based on where they are and what challenges that patient is facing, that becomes very much the focus of the therapy.

So, we're not necessarily visiting things from the past or even sometimes talking about worries about the future. It's a very present type of therapy. What is going on right now? What do we need to do to help you get through the now? And I think that tracks with the cancer experience being these different phases, and so the therapy will adapt with the patients' journey.

**Elissa:** Yeah, a lot of your presentation really focused on this being a supportive care for oncology, and supportive care is something that we talk about quite a lot on the podcast. We're literally referring to quality of life because it is so important. So, this really is just an additional way that we can improve the quality of life of some of the patients.

**Dr. Gilman:** Absolutely. I think that's really what the goal should be and is. And that's why I always emphasize I'm not looking to add any problems. I don't want to complicate things. You know, how can I help? If that's a medication, great. I also tell my patients all the time I will never put you on a medication that I won't ever talk about again. You know, we'll make sure we're constantly assessing, is this helpful? Is

this improving your quality of life? If at some point the answer is no, then maybe we don't need it anymore. It's a constant reevaluation of how to best support this patient where they are.

**Elissa:** So, if a patient was listening who is really struggling with their cancer care right now, what is the next step? How would they potentially get connected with a psychiatrist?

**Dr. Gilman:** The way that you would usually get connected with a psychiatrist would be talk to a provider who you're already working with. So, whether that's the oncology team; let them know that you're interested, so they can place a referral or if you are speaking with a therapist or a social worker, letting them know that you think that a psychiatry evaluation and participation in your care would be helpful. And then, the team can bring onboard psychiatry to meet the patient. But I think just reaching out to a provider that you trust and that already knows you, you can just let them know that you are interested in that, and they can make that referral happen.

**Elissa:** That's great. Now our final question for you today. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." 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?

**Dr. Gilman:** So, I love hope. I am a big, big believer that there is always something to hope for. And I think that often I'll talk about the other side of the coin. So, in the darkest moments, flip the coin over and look at the one hopeful thing, the one bright thing. And I think that finding something that is the window with the sunlight coming in in the dark room is that hope. And there's always something, as small as it might feel, there's something that's a reason to look out that window.

**Elissa:** Absolutely. Well that is wonderful advice for patients. So, thank you so much, Dr. Gilman, for chatting with us today and telling us all about your session. We don't hear about psychiatry a lot in the AYA cancer space. I think it was really



interesting, and I hope that it will be very helpful for our listeners to hear about that possibility and supportive care.

**Dr. Gilman:** I hope so too. Thank you so much.

00:30:32

**C. Robert Bennett, PhD, CPNP-AC:** Hi, my name is Robert Bennett. I'm a nurse scientist at the Mayo Clinic in Arizona. I have a couple different connections to blood cancer. First, my mom is a survivor of non-Hodgkin's lymphoma, and so that's been a big inspiration for my choice of career. And second, I work with adolescents and young adults living with blood disorders.

**Peter Drahms, RN, BSN, C.:** My name is Peter Drahms. I'm a registered nurse. I currently work as a travel nurse in Central New York, so I do spend a lot of time with oncology patients. I also have ten years of experience as a bedside nurse on an oncology floor in central New York state.

My personal connection to cancer is with both of my parents. My father has multiple myeloma, and he recently had a bone marrow transplant for that and has ongoing treatment.

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

**Dr. Bennett:** So, the title of our session was "Navigating Social Support Needs After 'Cancer Ghosting.'" The reason this was important is because so many of our patients have expressed feeling like their friends have abandoned them once they start cancer treatment and often wondering why; and, ultimately, blaming themselves as if they caused their friends to not be present.

**Elissa:** Yeah. I think that's a really, really common thing, for all ages, not just AYAs but sometimes people just don't know what to say, or they say the wrong thing or they just leave.

Now, a few things that you mentioned. You mentioned a catch it, check it, and change it. Could you explain what that is?

**Dr. Bennett:** Sure. So, these are some of the tenets of cognitive behavioral therapy that people can actually use on themselves to, when they have a negative thought, catch the negative thought in its tracks and identify that this is not a productive thought that's serving me. And then, to check a thought is essentially challenging if a thought is valid or not. Is this true or really could it be something else? And then finally, change it is a way of inserting a newer, more positive, more realistic thought that better serves you. And so, this is something that people can do whenever they're having thoughts that perhaps they did something to cause people to not be visiting them or any other negative piece in their life to cognitively reframe something that's negative into something either potentially positive or at least better.

**Elissa:** You asked a question on your slide. Why is it hard to say I care about you or, on the flip side, I want to feel like you care about me. So what is the answer to that?

**Peter:** So, I think the answer to that can be different for everyone. And it's important that, number one, we keep the lines of communication open and that we're self-aware. Whether you're a caregiver or you're a patient, it's important that you do your best to voice your needs and to try to articulate what it is that you're looking for in your relationship.

So, if you're a patient, maybe it's important to let your friends know, "Hey, today's a great day for a visit" or "Maybe I need some time to myself because I had a really rough day, and I just want to rest and have some time alone today."



As a caregiver, it's important to be able to reach out to your friend or loved one who's in the hospital or getting treatments and to be able to say, "Hey, what are some things I can do to help you?" "Would you rather have a visit today," or "Do you want to talk on the phone," or maybe social media could be a better outlet.

But really, I think what it boils down to is being able to have that honesty and trust level with your loved one so you can communicate the best way to have a mutually supportive relationship.

**Elissa:** One thing that stuck out to me was when you talked about disappointment and it being really a function of expectation versus what reality actually is. But I love that you continued on with that and talked about removing the illusion. Can you explain that?

**Dr. Bennett:** In terms of removing the illusion, we have our preconceived notions about the way life should be, would be, or could be. And these are just constructs that we create in our head. And when they don't come true, a lot of times it causes disappointment, frustration, and negative feelings. So, by learning to separate what we had hoped for versus what is true, it makes the truth a little bit more palatable.

**Elissa:** Another thing that you discussed was with cancer ghosting, patients can often feel like it's something about them, right? But that's not always the case. There are alternative reasons, whether platonic or romantic. Could you explain those?

**Peter:** Sure. So, there are many reasons why people maybe feel comfortable or don't feel comfortable going to the hospital. And these things can certainly have an impact on a relationship, whether it is platonic or romantic. Maybe someone has a difficult time being in and around hospitals or being in and around people who are ill. Some people have legitimate fears in that regard. On the more romantic side, maybe the person doesn't feel a chemistry with you, and maybe it doesn't have anything to do with a cancer diagnosis.

In any event, with these situations, it's important that the conversations continue to flow and remember that there may not always be answers or may not be the answers that you're looking for. In the end, it's important to be able to forgive another person, forgive yourself, and move forward to the best of your abilities.

**Dr. Bennett:** I think one of the other things to consider with that is that supporting someone who has a serious illness like cancer requires a lot of maturity that someone might not be ready for. And these are very adult problems, and someone who is an adolescent or young adult might not be ready to handle it, like developmentally their brain is not at that stage.

And so, expecting that of someone else or someone expecting that of themselves, it's a lot to handle. And it's just not necessarily a reasonable expectation at that point. It doesn't mean that they're not a great friend or don't care, or dearly love someone, it's just that they don't have what they need to support someone in that way yet.

**Elissa:** So, what advice would you give then to people who are listening who would like to support somebody going through cancer but may not know how?

**Dr. Bennett:** I would say starting with the little things, such as gestures. You can send someone a card. You can send a text, just some sort of subtle way to let someone know that you were thinking of them or that they're in your thoughts, that your friendship matters. I think that goes a long way. And if you're not comfortable visiting the hospital, there's other subtle ways that you can show a person that their friendship matters to you.

**Peter:** Another aspect of this that Cary [Robert Bennett] and I discussed was the importance of having a social liaison or a wingman. And what we mean by that, is just having someone in the hospital that you can trust that can communicate your needs to people maybe on the outside – your social groups, your friends, your family.

So, sometimes as a caregiver, it might be easier to take the less direct route and speak with that wingman, and maybe discuss what the best options might be to starting those supportive measures for your friend.

**Elissa:** What can the patient do themselves to maintain those relationships they have with other people?

**Dr. Bennett:** I think one of the first steps is being willing to be a little bit vulnerable and saying, "Hey, I'm in a really tough place, and I could use a friend right now. I don't need you to fix it. I don't need you to try and say the right words. I just need a friend right now and that's all."

**Elissa:** Yeah.

**Peter:** Another thing that someone in the hospital can do to maintain their support group and hopefully prevent ghosting is they can utilize resources either on a personal level, such as with the social liaison or also through the hospital itself. Talk with the staff at the hospital – your nurses, your social workers, your doctors and see if there are any other resources that you could tap into to help build that structural social framework so you can have the best outcomes possible.

**Elissa:** Yeah, I completely agree. And I think as a patient, I've told other people, just be present. You don't have to say the right things. Just be there. Be there in my life and just don't disappear. And I would hope that that could be most people in your life. But it's often not.

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

**Dr. Bennett:** I would tell them that even if they feel right now that they don't have a lot of social support, there are communities out there who get it. Just like being here



at CancerCon this week, and there's people who get it, who will embrace you and who can identify with what's going on in your life. So, I would take comfort in knowing that there's other people out there like me who are experiencing what I'm experiencing and that although things might feel lonely right now, there's opportunities out there for engagement.

**Peter:** I think I would tell people not to put too much pressure on themselves. I would encourage them to reach out to the supports that are out there. And CancerCon is a place where you can tangibly see how much support there is. It's a very therapeutic environment to be in. So, if we can take just a small part of this and bring it to someone in a hospital somewhere in the world, I think it would make a huge impact.

The other part of that is I think hope is a state of mind more than it is a fleeting emotion. And certainly throughout the diagnostic process and through the treatment process your goals may change. And it's important to maintain a level of hope, regardless of what your goals are. So, I think it can be a dynamic feeling to have; but it's something that can sort of override everything and be a guiding light. So, it's important to hold onto hope.

**Elissa:** That's great. Well, thank you both so much for joining us today. We really appreciate you and absolutely loved your session. I think a lot of people in the room resonated with it, and hopefully our listeners will as well. So, thank you again so very much.

**Peter:** Thanks, Elissa.

**Dr. Bennett:** Thanks, Elissa. Always a pleasure.

**Elissa:** This concludes our second episode podcasting live from CancerCon 2024. Be sure to tune into the prior episode where we interviewed young adult patients and



survivors at CancerCon to hear their thoughts on transitioning from their oncologist to a primary care provider.

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. Did you know that you can get more involved with *The Bloodline* podcast? Be sure to check out our Subscriber Lounge where you can gain access to exclusive content, discuss episodes with other listeners, make suggestions for future topics, or share your story to potentially be featured as a future guest. You will also receive an email notification for each new episode. Join for free today at [TheBloodline.org/SubscriberLounge](https://TheBloodline.org/SubscriberLounge).

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](https://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](mailto: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](https://LLS.org/PatientSupport). Young adults who are age 15 to 39 are encouraged to visit [LLS.org/YoungAdults](https://LLS.org/YoungAdults) for all the resources that LLS has to address your unique needs. For more information on CancerCon and Stupid Cancer, please go to [StupidCancer.org](https://StupidCancer.org). All of these links will be in the show notes or at



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