

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Coping with Cancer as a Couple'

Description:

Join in as Shona sits down with Ellen Polamero onsite at CancerCon 2019. Ellen is a clinical social worker at City of Hope in Duarte, California. CancerCon is an annual conference held year by Stupid Cancer, an organization that provides support to young adult cancer survivors. This is the fourth year that Ellen has hosted a 'Couples Coping with Cancer' session at CancerCon and shares why it is important to her to provide this offering. On this episode, Ellen speaks about the impact of cancer, not only on the specific person that is diagnosed, but on the family unit as a whole and on intimate partners specifically. She describes the challenges a couple may experience, expectations that couples may place on themselves, the importance of communication and various resources available to couples. Ellen shares key takeaways to help couples navigate their cancer journey.

Transcript:

Shona: Welcome to The Bloodline with LLS. I'm Shona. Thank you so much for joining us today. I am recording on-site at CancerCon, taking place this weekend in Denver, Colorado. Here with me today is Ellen Polamero, a clinical social worker at the City of Hope in Duarte, California. Thank you so much for joining us today.

Ellen: Thank you, Shona.

Shona: So, for those who don't know, CancerCon is held every year by an organization called Stupid Cancer, which is an organization that provides support to young adults who are currently diagnosed with cancer or who are cancer survivors. And LLS attends every year. We, have a presence here because around 40% of CancerCon attendees are blood cancer patients. So, we come here to provide resources and talk to patients in real time. So Ellen, you are here with us today. Could you tell us a little bit about your background and what brought you here to CancerCon and what brought you to your profession, in general?

Ellen: Sure; absolutely. So I have been in oncology for about 10 years and, actually, my start was with hematology and blood cancer patients so I worked on our Bone Marrow and Stem Cell Transplant Unit at the City of Hope for the first several years that I was there and ran The Leukemia and Lymphoma Support Group on campus; so thanks to you guys for the support you offer to those hospitals that are hosting

support groups. And during the time that I was working in hematology, I really saw the impact of cancer, not only on the specific person that is diagnosed, but on the family unit as a whole, and on intimate partners especially. And the City of Hope has what is a pretty comprehensive program supporting partners, couples' intimate relationships as people are going through cancer together. And so, a few years ago, I had the opportunity to join this team and start working with couples and it felt like a really natural segue way for me—having being in that area that I could focus on, caregivers, and then getting to focus more specifically on the partnership—the intimate relationship that couples have during this time. So, that's a little bit of my professional history and then, CancerCon, I had been coming—this is my 4th year at CancerCon. I have been hosting a Couples Coping with Cancer session and this will be the 4th year—so for the past 3 years and this is one of my favorite things that I do every year. One of my favorite conferences, hands down. And the people at Stupid Cancer are incredibly passionate about the work that they do and the energy at this conference is unmatched.

Shona: Yeah.

Ellen: ...in my experience anywhere else.

Shona: Absolutely.

Ellen: Yeah; so, I just—I love coming. I always go back feeling refreshed about my work, and the patients that I work with, and my life, in general. I always feel like a better person when I come back from CancerCon. And I think, you know, that one of the things about supporting the AYA communities, specifically, is that working in a large cancer setting, I know that when you walk the halls, young adults are not the faces that you see the most often. They tend to be in the minority. And so, for people who are young adults diagnosed with cancer, they feel alone. They feel like an anomaly. And being able to have this resource to connect them to, this community to connect them to helps them feel a little bit less alone so I am just hugely thankful that Stupid Cancer and CancerCon offer this for our young adults out there.

Shona: I completely agree. I couldn't agree with you more. Could you tell me a little bit more about the Couples Coping with Cancer Together program at Hope.

Ellen: Sure! I could! It's a program that's specifically for intimate relationships and that can be marriages, spouses, or just long-term partners, girlfriends, boyfriends; it doesn't matter. If you are in a relationship and you consider that person to be your significant other, we are there for you. We offer, kind of, 3 different types of support at the hospital. The broadest type of support we offer is our support group that is specifically for couples, but not specifically for a certain cancer diagnosis. So, people come with all different diagnoses. We don't focus in a lot on the medical side of cancer. We focus more on the emotional impact on the relationship. So, it's a pretty

special group. The people that come, come ready to be very honest and vulnerable and talk about how this is going to impact in their life and how they want to make life better as they are going through this together. So, that's sort of one branch. And then, we have what we, kind of, refer to as our preventative care, or inoculation, and that's a 30-minute session typically that we do with people, patients and partners who are newly diagnosed to talk about what to expect when it comes to a cancer diagnosis, the impact on the relationship, stress, how stress impacts people differently, how they can best support each other, better communicate with each other and thrive, really, during this time of treatment and, then, recovery as well. And then, the last thing that we offer to patients and partners is ongoing counseling if they need more support than just that one-time session or the support group offers. We meet individually with couples to help support them in rebuilding or problem solving in their relationship as they go through this time.

Shona: That's excellent. That's really excellent. Is this type of program offered at many other hospitals or is City of Hope a pioneer in that aspect?

Ellen: As far as we know, it is not offered anywhere else so this was really a pioneering program. So there definitely are support services for couples at other hospitals, but we don't know of anything else that is this comprehensive. So, we are really lucky to have the support of the hospital as well as actually support from some past patients and partners that have, you know, come to help us build this program to be able to offer this type of comprehensive support.

Shona: Yeah, that sounds so important to be able to offer that type of program because, you know, if you are in an intimate partner relationship—if you're married, have a spouse, boyfriend or girlfriend, you really do take on that diagnosis together.

Ellen: Absolutely.

Shona: I was in a session this morning hearing the young caregiver talking about caregiving for her husband and the challenges that she found. So, what can a caregiver expect when a partner is diagnosed?

Ellen: I think that one of the expectations that's helpful for both people in the relationship to have, not just the caregiver, but the partner as well, is that cancer is hard and relationships can be hard as well; and that when you put cancer and relationships together, they don't tend to get easier. They tend to face challenges. Challenges rise to the surface. So, I think one of the things that often happens—one of the things that I see with couples is that when their loved one is diagnosed with cancer, they have this expectation that they put on themselves that they will suddenly become super-human...

Shona: Hmm; hmm.

Ellen: ...and be able to do all things you know, with grace, and skill, and ease and, even though they still have to run the rest of their lives...

Shona: Right.

Ellen: ...and manage everything else that they were managing before cancer, that they will take on the full responsibility of caring for their partner as well and that it won't be a problem. I won't say it won't impact them, but that they can do it! You know, no problem. They can do it; and that they can do it without asking questions without needing help or support, or instruction, or anything along those lines. It's this sort of funny expectation that we put on ourselves that we should be able to step into this perfect partner-caregiver role and not falter.

Shona: Hmm; hmm.

Ellen: And I think that this happens in all varieties of relationships, not just in intimate relationships, but when somebody is diagnosed, when cancer enters into the picture, you want to become the very best version of yourself and you want everyone around you to become the best versions of themselves as well, that that's really not often the case; that often the stress is what really makes us struggle with individually and in our relationships.

Ellen: And that we need to get ourselves that grace, and that permission, to not be perfect either as the caregiver or as the one that is diagnosed with and in treatment for cancer.

Shona: So, great transitions to what I was going to ask you. What can the patient expect from their perspective when they are in a relationship or they are part of a couple?

Ellen: From their partner or just in terms of the ...

Shona:in terms of how that diagnosis will affect their relationship with their partner.

Ellen: I think that the safest expectation is simply that it will impact your relationship and that if you go into this intentionally in your relationship, it can impact it for the better; that a lot of couples, a lot of relationships strengthen, people grow closer, they learn more about themselves and about each other during this time and they come out the other end more connected, better able to understand and support each other than

they went in at the beginning. But, again, that's not going to happen magically that it's going to take some intentional work on both sides. And I think, the other thing,

and you sort of alluded to this earlier when you were talking about the person who was speaking at the session this morning and the impact of that caregiver, is that this impacts caregivers just as much as it impacts patients. And remembering that, as the person who is diagnosed, remembering that your loved one is struggling as well; that they are going through major life changes watching their partner, their spouse having to go through treatment, have to cope with all of these challenges is hard on that person as well. Just keeping that in mind, having that compassion for them, that counts for a lot.

Shona: Absolutely; so, you know, you mentioned that, oftentimes, the relationship becomes stronger and the couple grows closer. And I definitely—from my work with LLs and working with the patients that, you know, come to us that use our resources, you know, I've definitely heard that—heard of that happening, but I have also heard the opposite as well.

Ellen: Sure.

Shona: I have heard that, you know, I thought that my spouse was going to be there for me and then she wasn't; or I thought that my spouse was going to offer me a lot more support and he did not deal with it in the way that I thought he was going to. Can you speak of that a little bit as well and what may be happening in those situations?

Ellen: Yeah; yes; definitely. So, and I think that this is actually going to be one of the golden-nugget take-aways, hopefully.

Shona: We love take-aways on the podcast. So, if you don't listen to anything else, listen to this.

Ellen: So, one of the things—and this, again, goes back to sort of that sense of responsibility that I think people take on for being super-human is that I think that we fall into these traps of assuming that our partner knows what we need and assuming that we know what our partner needs. And this happens in both directions. It happens for patients and survivors wanting their caregiver, or their partner, to instinctively know exactly how to step in and take care of them and it happens with the patient or survivor thinking that they understand what their partner is going through. And this can lead to all sorts of disasters. All sorts of problems. Because, really, again, in like, the best-case scenario, none of us can read each other's minds. None of us actually intuitively know what our partner needs even though you might get better at that with time the longer you've been with somebody. You might guess better than you used to or you might know because you've learned more about your partner than

you did at the beginning, but cancer sort of throws everything into, you know, a whacky blender and makes things that might have been true for you before, or true for what you needed from your partner before, not true anymore at this time. So, in those situations, I would say the very best thing that you can do in your relationship, on both sides, is to get rid of those assumptions that you think you know how to take care of your partner, in both directions, and that you think that your partner knows how to take care of you. So, stop all of the mind reading, stop all of the testing because I think we sometimes do that in our normal relationships as well as during cancer—if he knew me well enough—if she loves me enough, all of that thing, then she would know, I wouldn't have to ask; I wouldn't have to instruct. But that the greatest gift that I think relationships can give—people in relationships can give to each other, during this time, is to simply say. Say what you need. Ask for what you need. Teach your partner.

Shona: That's so important because, if you think about it, cancer is a whole new uncharted territory for both of you so you might think that, well, she knows what I like or he knows what I like; and I made him chicken soup when he had the flu so it's might be similar to caregiving, but...

Ellen: Right; absolutely.

Shona: ...everything is so different and the needs that each patient has are completely different. So, it's a new world and you're right, you don't—you can't just assume that your partner is going to be a mind reader. Communication is very important. And learning communication techniques is important, too, because sometimes you can't just—it's very difficult for you to verbalize what it is that you're feeling or needing at the moment.

Ellen: Yeah; absolutely. And I know because sometimes I say this to women, in particular, because I think we tend to be a little bit worse about wanting our partners to intuitively know exactly what we need. So, sometimes I will say this to women and say, "look, you just—you really need to tell your husband, your partner, your spouse what it is that you need from them." And she'll say, "but what if I don't know for myself?" And then, I say, "that's okay; if you don't know, say, you don't know right now and right now all I need is for you to come over here and give me a hug, or seat next to me on the couch and let me cry; or leave me alone for a little bit while I work things out." But it doesn't have to be an "in the moment" answer, but it's the intention that you're going to give those instructions in some way give that guidance to your partner without just expecting from them that they're going to figure it out on their own.

Shona: Okay; so, we're here at CancerCon, which is, you know, is a conference for young adults. So, I feel like a young adult couple will have different needs than,

perhaps, a couple that has been together for 40 years. There's a lot of different life events that might be going on for the young adult couple as well. So, what specifically

do you think that this young adult community might need as far as, or advice that you might give them from the perspective of someone who works with couples?

Ellen: So, actually, the first thing that I would say is that, surprisingly, I find that couples, young and old, tends to struggle with a lot of the same things and tends to benefit from a lot of the same things.

Shona: That's very interesting. So, yeah, you think that there might be completely different sets of needs, but...

Ellen: Not always; and I mean this is not an across the board thing, of course, I mean, definitely, I've sat down with people that are, you know, 50 years into their marriage and they're clearly in a different place than people who are...

Shona: Right.

Ellen: ...young and might have been in that stage of establishing careers and thinking about families and all the other things that go along with being a young adult, but I think a lot of the foundation, when it comes to communication and stress and support, is the same.

Ellen: So, really, I think that some of it is just about acknowledging and giving yourself permission to learn and grow together. And so, if we are talking about a couple that's already in a relationship, we're not talking about dating right now. We can talk about that in a minute, as well. But if we are talking about a young adult couple that's already in a relationship, that's already trying to navigate all of the changes that they are going through during this stage of life, then I think that the very first thing that you can do is to take that big step back and say, "okay, we've got a lot on our plates and we are going to take it one step at a time and try to figure it out"; and know that things are going to change, but things were going to change anyway during this period of time. We are going to face all of these challenges as we blend our lives together and now, we are facing even more because there's this other layer of health struggles added on top of it.

Shona: So, one thing that I think of when I think of, you know, younger couples or couples earlier on in their marriage is there might be more to do than just take care of the person who is sick.

Ellen: Absolutely.

Shona: You might have young children and you might have aging parents. So, you might get pulled in lots of different directions. So, what are some needed coping strategies or behavioral tips that you can give to people who might feel that they don't

have a whole lot of time left for themselves; or they might be at the end of their rope as far as caregiving and they might be close to experiencing burn-out. Because of that stage of life, you just have a lot going on.

Ellen: Yeah; yeah. So, first and foremost, I would say, "calm the troops." And I know there's a wide range of how much support people have available to them depending on if you live close to family; if you've moved into a new area and don't have that support network built up, but if ever there was a time to ask for help, this is the time. So, not to have that expectation that you are going to take on all things. Liked we talked about—you are not a super hero. You can't do all of this. You need to be able to ask for help and prioritize the other things in your life as well as your partner who you are taking care of. You need to acknowledge the responsibility of raising a family, if you have one, maintaining a job so you can have health insurance so that you can continue to care for your spouse who is going through all of this. And those are all—those are all valid and it is not something to feel guilty for. And I know there is a lot of that guilt for people when they have to leave their partner either in the hospital or when they can't come to all of their appointments because they're working. They're at school. They're wherever else they have to be. But letting go of that sort of "I'm responsible for 100%" and being willing to ask for help, and when people offer, accepting it.

Shona: Right. It's so hard for us...

Ellen: Right. It's so hard.

Shona: ...to ask for help or accept help. Like you were saying, you kind of want to take on this super-hero...

Ellen: Yeah.

Shona: ...mentality. I can do it. And, then, you know, there's the when you ask for help, there's always that guilt of being a burden and, you know, it can be very hard to get over to yourself that you do need assistance. And, you know, something that I was thinking about as you were just telling me this was, you know, this same young lady in the session this morning saying that any time she felt that she wasn't devoting energy to her husband, who was the one who was sick, she felt guilty about it. And I imagine that translates as well to asking for help. You know, if you think, "oh, my mother-in-law has a—has a spare hour ", that you want—you would probably direct her to help the patient instead of maybe taking some of the load off yourself as a caregiver.

Ellen: Right. Yeah.

Shona: So, I think it's important to kind of know that it's okay to ask—for help and it's okay to, you know, like you said, share the load with the people that care about you.

Ellen: Yeah; yeah. Even more than okay. I think it's essential.

Shona: Necessary.

Ellen: Yeah; absolutely. And this is probably a really important conversation to have with your partner first and how, because they might be able to offer some wisdom and insight from the perspective of a person that's going through this, to be able to say, "hey, I can see that you're carrying this, this, this, and this and let's get some help for you" because a lot of times the person that has cancer worries about their caregiver...

Shona: Right.

Ellen: ... and wants to be able to take care of them, help for them. And maybe it's easier for that person to reach out to your family and friends and say, "hey, my husband, my wife needs a break. Can you step in and do x, y, z for us so that he or she can go do whatever he or she needs to do? And, it can be selfish. You need to be able to be selfish during this time because you have to take care of yourself as well.

Shona: You have to take care of yourself and your house and your mental well-being or else you are not going to be able to be a good caregiver.

Ellen: Yeah; yeah. And you know that's one of those things that I know that we talk about in the cancer community and caregivers still resist. Partners still resist. They're like, "no, no, this isn't about me." It's about somebody else and it's, you know, "I'm here to care for them. I have to be self-sacrificing". And "yes; but", right? Yes; you do. You are there for them. Yes; you do have a loved one going through cancer, but if you don't take care of yourself, then where's that person going to be when you land in bed with the flu, or whatever it is. When you are incapacitated because you've run yourself dry taking care of everybody else in your life. So, it's more than just fluffy encouragement. It's definitely a necessity.

Shona: Right. So, switching gears for just a second. You had mentioned dating—that we could talk about dating in a second. And I know you mostly work with couples who are already in relationships, but especially for the young adult community, many of them are single, dating, you know, re-entering the dating world after a cancer diagnosis and there are so many challenges that come along with that. I spent a lot of

time with our patients online, via our online forums, for the patients to talk to each other and LLS as well and the things that I hear from patients who are, not currently in a relationship, the fear. How can I possibly take somebody out on a date when I'm struggling financially because of my diagnosis? Or, you know, I don't know the right

time to tell someone, to disclose my cancer diagnosis if, you know—if we're out on dates. You know, someone mentioned that they just kind of took themselves out of the dating world completely because it's like, "you know what, this is something that I don't think I want to delve into right now." It's a whole other, like, loaded bag of things that I have to deal with. So, can you talk a little bit about what can someone expect when they're maybe, like, getting back into the dating world?

Ellen: My first reaction is that everybody is going to be different.

Shona: Right.

Ellen: And that there's probably no rule of thumb about when you talked about that person that had decided to pull themselves out of the dating world. Like, good for them! Good for them for having that insight that they needed to do more work on themselves to heal, to recover, to be ready and that's fine. That's good and we should be selfish with our recovery before we step back into dating. And when to disclose, you know, it probably really just depends on if you are out there dating because you just want to get back out there and date and have some fun and live life a little, or whether you've met a person that you really like and you think you might want to build a relationship with. And then, in those cases, it might be more important to think about disclosing earlier because it's something that you want to be long-term and you want to start on that footing of being open and putting all of your baggage out there. You never want to do that on the first date. I know, it's been a long time since I've been in the dating world. Just to be honest here.

Shona: And you know, it goes without saying that the dating world is tough for everybody. It is not always fun to be, you know, single and dating. It can be constantly putting yourself out there, even after you might get hurt or feel rejected and then you are adding on top of that the way you might be feeling because of what you're going through with cancer can just be, like you said, it's a lot to deal with.

Ellen: Yeah; yeah. I mean, one of the first things that I said was relationships are hard. They are hard when you're in them. They're hard when you're not in them. They're just hard.

Shona: Relationships are hard even without, you know, illness or cancer, or any of these life events impacting that maybe you didn't even foresee. Relationships are hard to begin with.

Ellen: Yes.

Shona: Relationships take communication and working together no matter what so...

Ellen: Yeah; yeah. And I can imagine when you're entering back into the dating world and sharing your story that it becomes one of the stories that you share. Just like when you were dating before cancer, there were probably stories that you shared then as well, but at a certain point, you had to decide if you trusted somebody enough to share those pieces of your history. And, obviously, depending on where you are in treatments and how much cancer is impacting you on a day-to-day basis still, it's a bigger story or a smaller story. But getting to that place that you feel strong enough in yourself, strong enough in the person that you are dating, trusting enough to share pieces of that or all of that with them and then remembering that, most likely, they don't know very much about what it is like to be a young adult cancer survivor because most people don't.

Shona: Right.

Ellen: And you might have to kind of start from the beginning.

Shona: Right; from scratch.

Ellen: Yeah; yeah.

Shona: Exactly; exactly. So, one thing that I wanted to ask you while you're here. You know, here, at LLS, we believe in the power of resources. So, and I know that you are a social worker so you believe the same thing. So, what resources are available for couples who might not live in—near the City of Hope; who might live somewhere else who wants to benefit from some of the work that you've been doing?

Ellen: Yeah; so, I always start with telling people to go to wherever they are either in treatment or have gotten treatment in the past and ask because I find that a lot of people have never even taken that simple step of asking what resources are available. So, if you have social workers, chaplains, patient navigators, patient resource centers, any of those labels, those are good places to start and say, "do you have support groups? Do you have individual counseling? What is available through my hospital, my medical center?" And, if you are not connected with a hospital or medical center, but you are near one, a lot of times those groups that are offered, the support resources that are offered are open to the community as well. And this is another, like, little known secret. Nobody realizes that support groups that are in hospitals are almost always open to anybody in the community, not just the patients at that hospital. So, that's sort of, like, a quick way to get started.

And then, the next thing that I would suggest is getting online. So, if you don't get any information through your medical center or through your clinic, that going to some of the major reputable organizations, like The Leukemia and Lymphoma Society, like the American Cancer Society and finding out what resources they are aware of, that

are in your area. If you start goggling Couples and Cancer, you'll find a lot of articles and a lot of, both like research-oriented articles that might be a little bit less interesting, but also some of the just sort of first person perspectives on what it's like to go through this and how to better communicate and support one another. So, that sort of would be step 2 of finding those resources out there in the community. And then if you are really struggling, I would encourage people to seek out therapy. , clearly, I'm a biased opinion, but I think couples therapy can be helpful for huge numbers of reasons across broad spectrums of our lives, but this in particular; just like this is the time to ask for help as a caregiver and as a patient for those practical things, this is definitely a time to ask for help navigating the challenges that you are experiencing in your relationship. So, look in your community for a therapist that has cancer experience, that has relationship experience. Calling him first, doing little phone interviews, seeing if it feels like it might be a good match. That can be incredibly helpful as well.

Then, I did want to throw out one other resource that came across my desk recently through the Dear Jack Foundation. They sponsor retreats for young adult couples who have gone through cancer treatment together recently. So, you can hop on their website, too, and see what they have coming up in the future.

Shona: Excellent. Thank you. I would definitely encourage all of our listeners to do exactly that. And, of course, I will take this opportunity, while we are talking about resources, to talk about some of the resources that we, at LLS, offer for young adults and for all of our patients. In addition to this podcast, we have educational publications that you can browse. They are completely free to download or order. Browse by disease interest. We have an online chat, which is moderated by an oncology social worker. So, that is also divided up by diagnosis, but also there's a young adult chat so you can chat with other young adults. And, similarly, we have an online patient forum called LLS Community. So, less real time in the chats, but it functions like a social media page. We also have educational resources in there, but you can go on there and join groups corresponding with who you want to talk to and just have these conversations. And, one of the things that we do at LLS Community is that we regularly survey the community—ask, you know, questions. We often ask about relationships. You know, how is your relationship with your spouse? What challenges have you found since your diagnosis? And then, you know, people will comment about it and then conversations will start that way. So, this is a really great opportunity for people to talk to other people if you have, you know, gone through similar things; offer perspective; offer guidance and support and it's really amazing. So, I encourage all of our listeners to check these resources out. They can be found



on our website www.lls.org. We have tons of resources available for our patients and caregivers and we encourage you to check them out.

So, Ellen, is there anything else you would like to leave our listeners with? Any more nuggets of wisdom or take aways?

Ellen: The last thing that I would like to leave our listeners with, especially those who are in relationships and those who are thinking about getting back out there and dating, is to remember to have fun. And I think that that is really what CancerCon is all about. What we're here for is to, you know--their tag line "get busy living", that you don't want to slip into that position of being a caregiver and patient forever; that you want to still be husband and wife, spouses, partners, romantic. You still want to do the things that you love both individually and together; the things that spark joy in your relationship and that keep you connected. And that it is important to remember that those don't have to be big, that they can be very small and that small is just as important as the big things because I know a lot of people get stuck in that trap of "oh, we need to plan our next big vacation" and then they get thwarted. But little date nights, that special moments to connect talking about things that are not cancer and treatments and all of the fun stuff that goes along with it, those are hugely important during this time. Don't let go!

Shona: Don't let them go! Relationships are supposed to be fulfilling and, you know, all about love.

Ellen: Yes; yes; exactly; absolutely.

Shona: Well, thank you so much for joining us today. I know you had a really busy day here at CancerCon. You have a lot to do. So, thank you for taking some time to talk us and our listeners at home. I hope you have a great rest of your day here at CancerCon.

Ellen: Thank you. Thank you.

Shona: And thank you for joining us.

Ellen: It was good to be here. Thank you so much.