

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'How to Become a Great Patient Advocate'

Description:

Join us as we speak to Erin Galyean, a pharmaceutical sales trainer, professional speaker, and published author. In this episode, Erin tells us how, after losing her father to non-Hodgkin lymphoma and then helping care for her sister, who was diagnosed with the same disease 20 years later, she learned that family and friends who are not the primary caregiver can still become great patient advocates. Erin shares strategies on how to effectively advocate for a patient, the different roles that friends and family can play on the support team and how, even if you live far away from a loved one facing a cancer diagnosis, you can still make a difference.

Transcript:

Elissa: Welcome to *The Bloodline with LLS*. I'm Elissa.

Edith: I'm Edith.

Lizette: And I'm Lizette. Thank you so much for joining us on this episode.

Elissa: Today we will be speaking to Erin Galyean. Erin is a pharmaceutical sales trainer, professional speaker, and published author. In 1997 she lost her father, Mike, to non-Hodgkin lymphoma; and in 2018 she lost her sister, Meghan to a rare lung disease caused by the same non-Hodgkin lymphoma diagnosis as their father. These heart-breaking life events, combined with her professional experience, taught Erin how to effectively advocate for a patient. As a result, Erin's vision in life is to share her knowledge with others so that they can do the same. Welcome, Erin.

Erin Galyean: Thank you. I'm so excited to be here.

Elissa: So, let's get started by getting in to know a little bit about you. Tell us about yourself.

Erin: Okay. So, I grew up outside of Philadelphia. For any basketball fans, I grew up in Newtown Square which is not far from Villanova University. And I grew up part of a big family. My immediate family was small, just one of three children; but I've this big Irish family, lots of cousins, and it was just a really fun childhood.

And my father, in 1997, as you mentioned, was diagnosed with non-Hodgkin's lymphoma. Now my father was just the energy of the household – big personality, lots of fun, loved to dance, and he was just great to be around all the time.

And so, this came as quite a shock. My father was 52 when he was diagnosed, and within ten months he actually passed away. So, it happened fairly quickly, from my family's perspective, and we were heartbroken because, like I said, he brought a lot of energy and happiness to our household.

So that happened, and then my brother, my sister, and I and my mom, we kept going; and we had our grieving process. And my sister and my brother and I continued to grow up, and we were young adults when that happened. I was 20 years old when my dad passed away, and my brother and my sister a little bit older.

And about 20 years later, unfortunately, my sister was also diagnosed with non-Hodgkin's lymphoma. Now we found out about it because she actually had sores in her mouth; and this had been going on for several months. And it seemed kind of odd, but she wasn't getting a lot of answers. Finally, they figured out that she had an autoimmune disease. And the autoimmune disease, we found out later, was caused by non-Hodgkin's lymphoma. The cancer caused the autoimmune disease; and then, unfortunately, the autoimmune disease caused the lung disease.

So, my sister's cancer, unlike my father's, was curable. My sister fought the cancer for five months; and she ended up beating it, which was awesome. That was such a great day. We were so happy for her because it was a tough time, especially, like any cancer patient going through chemo and losing hair, there's a lot that you go through – feeling crummy. In addition to that, she had this lung disease that she was fighting.

She was 47. She went from this young, energetic mom of two. She worked full time. We would always tease my sister. She can't ever sit down. She would have like five jobs. You know, all these side jobs because she had these little talents like calligraphy and coaching lacrosse and all these passions.

And suddenly she went from that person, who we'd always known, to really slowing down. And the lung disease just took a toll on her petite body, and she couldn't do the things that she used to be able to. So, her decline was quick, and really it was due to the lung disease, but it was the non-Hodgkin's lymphoma which caused it all.

So, my sister passed away in 2018. Again, it was another shock and blow to my family. I still think I'm lucky and blessed to grow up in the family that I did because we were close. And we weren't perfect. We had our fights too, especially in the bathroom, right? Girls fighting over the bathroom. But we were a happy family; we really loved each other. So, I am thankful for that and just sorry that we missed those amazing people.

Lizette: Your father and sister were both diagnosed with non-Hodgkin lymphoma. There's so many types of non-Hodgkin lymphoma. Do you know if they had the same type? It looks like they may have had different signs or symptoms.

Erin: Great question. They did not have the same type, and I have to tell you I was so naïve. Of course, I was young when my dad passed away; but I didn't know that there were multiple types until my sister was diagnosed. And I don't know which types they had. I'd have to ask my mom. She was their main caregiver, and her notes are meticulous; and she would know off the top of her head. But I know that they did have different kinds.

So completely random. We were always told that my dad's non-Hodgkin's lymphoma was not hereditary. Now I don't know if doctors would still feel the same way today, considering that was 1997.

Lizette: They are doing studies just to see, but typically with many of the types, it's not something that's considered hereditary. But again, now that we're seeing more families having the same blood cancer diagnosis, they are looking into it more and more these days.

Erin: Um-hmm, scary.

Elissa: What was that like then, after your dad had passed away, then 20 years later hearing that your sister also had non-Hodgkin lymphoma?

Erin: Yeah, it was so shocking. I was very confused. I will never forget where I was. My husband was the one who broke the news to me because my sister and I were best friends. We weren't just sisters. And she was this just amazing, kind sister. Even as a teenager she was kind to me; so, you know if you have teenagers, you know what that's like. You don't always love your little sibling, and she was even gentle and patient with me then. So, we were always close, and she said she couldn't do it. She couldn't tell me. But she wanted me to know, so she called my husband and had my husband tell me.

So, I know it scared her, but she's a fighter. She was an athlete, and she said, "I'm going to beat this." And her number one, which if you're a parent you will get this. Her number one focus was her girls. And she said to the doctor, "I've got a lot of living to do. I can't give up. So, I'm going to fight this." And she did. She gave it her best fight; and her body just didn't want to do it anymore.

Lizette: You're right. I could definitely relate as a mother. You want that time. You want more time always to see your kids grow up.

Erin: Yes. Um-hmm, and that's the most heartbreaking part of it. Of course, I'm sad for myself, but I'm really more sad even for my sister and her daughters.

Lizette: Yeah.

Elissa: Now were you living in the same area as your sister and your dad when they were going through the cancer treatments?

Erin: No. I mean what a situation I was dealt, huh? I didn't even get to be near them. So, when my dad was sick, I was a college student; and I went to the University of North Carolina. And like I said, I grew up outside of Philadelphia, so many states away.

But I was young and when you're young, you think everything's going to be fine and work out. Which is not a bad thing, because I had a very positive attitude towards it. And so did my family. We weren't doom and gloom about it. And then with my sister, unfortunately, when she got sick, she lived in Charleston, South Carolina; and I live in Dallas, Texas. I had a two-year-old at the time, so I did my best going back and forth; and I am so thankful I got all the time I did with her.

So, if there's anyone listening that doesn't live close, and I know we're going to talk about it, but there's still a lot that you can do for your loved one who's sick and who's far because it's frustrating and it's upsetting; and you feel like it's out of your control, which it is. But there's still things you can do to help and support.

Edith: Wow, you refer to yourself as a patient advocate. What is the difference between that and a primary caregiver?

Erin: So, I've had this conversation with so many people, just one-off conversations. I think they can be the same thing, but they're not always the same person. So, a caregiver, obviously, takes care of that patient on a day-to-day basis; and sometimes they need to also be the patient advocate, so meaning you go to the doctor's office or you're at the hospital. You're being the voice for the patient, taking notes, like I mentioned my mom does. And just basically being there for them as a voice in addition to the caregiver would do the day-to-day caregiving. You know, all of the little things you do, like the medication and maybe toileting and all those different things that can come about.

When you're just a patient advocate, you're not always the caregiver. So, I find that when I talk to people, a lot can relate to this. So, I am a great example of someone who was the patient advocate but not the caregiver. I didn't live near my dad. I didn't live near my sister, so I couldn't do the day-to-day caregiving. But I could advocate for her from afar and when I visited her. So, I could email physicians. I could make phone calls. I could have discussions with family members and kind of take that off my sister's plate or my mom's plate and say, "Here's what's going on with Meghan. Here's ways you can support." So, I could do a lot of things to support my sister and the rest of my family, including her husband and her kids without having to be just around the corner.

Elissa: There's so much stuff to be done; and it either usually falls on the caregiver or the patient, and that can be really hard. I remember going through my own cancer treatment, and people were like, "Why haven't you updated your CaringBridge yet?" And I'm like, "I am tired. I am really tired."

Erin: I've got other things to do.

Elissa: I'm sorry. No, I was like, "Why am I having to say sorry to everybody because I haven't updated my journal entry yet?"

Erin: True, and you shouldn't.

Elissa: So, there is a lot to do, and so I'm excited to get into what that all means and the different duties and things like that. So that's great.

Now as many of our listeners know, there is a tremendous emotional impact of having a loved one diagnosed with cancer and adding onto it that your father and sister had the same diagnosis. What was that like for you personally?

Erin: Yeah, that's a really good question and one I don't talk a lot about, but I think it's important to talk about our emotions because I think sometimes, we don't want to

address them, and we need to. That's what helps you to stay healthy and get through it.

The biggest one for me was anxiety. I don't think I really knew – and this kind of sounds crazy because I'm not that young – what anxiety, I've had anxiety throughout my life, of course, like most of us do, but what it was and could identify that tightness in my chest until my sister got sick because now my biggest fear came true.

When my father passed away, my biggest fear was another family member that was close especially passing away or getting sick. And my sister was my best friend. This was my ultimate nightmare of her being diagnosed with not only the cancer but the lung disease which was aggressive and rare.

So, I had a lot of anxiety throughout that time, and to get through it, I have some amazing friends. Two of my best friends, one's a three-time cancer survivor. The other one is just a rock, and she lost her father about the same age that I did, so she understands going through cancer and as a family member. And then, of course, great family members; and then I did see a therapist.

And so, if there's anyone that kind of is hesitant about therapy, I think sometimes in our society we don't want to go to a therapist, but I highly recommend it. Having a neutral party that's a professional that you can speak to, I think every single human being should go to a therapist, whether you're dealing with an illness or not.

We aren't taught how to deal with our emotions as we're growing up. We're taught math and lots of other things like manners. But we're not always taught how to deal with our emotions, and I think that's a really key part to life.

Lizette: It really is, definitely. A good point that you bring up is that we're not quick to say that we're seeing a therapist. It's okay to say we're seeing our oncologist, but you're still not really saying, "We're going to our therapist to many people."

Erin: I hope that Simone Biles has helped with that. I mean how brave was she?

Lizette: I hope so. Yeah.

Elissa: That was amazing.

Erin: The more people, I think, that come out and say that I think the more people realize there's not a stigma around it; and that it's really important to take care of our mental health and deal with an illness whether you're the patient or the patient advocate or the caregiver or another family that's not as involved. Therapy can do wonders for you, and you just have to really be open to it and be honest, and I think that's hard sometimes.

Lizette: It definitely is, and it's really important what you're saying too is that it's not just a patient in this cancer journey. It's a whole community around the patient, so everybody really needs support. And how did you find support outside of your immediate family and friends? As a patient advocate, usually you're better at finding support services for yourself as well as your loved one.

Erin: Yeah, well the therapist was a big one for me because I could talk to her about everything that was going on, on a one-on-one basis in private. I will tell you that even after my sister passed away, I also went to a different therapist that was for grief counseling. So, what my recommendation is, if you have a loved one who you know has a terminal cancer, then I would start to see someone who is trained with grief counseling because they can go with you through the whole journey because you're already in a grief process, right?

Even if, they've got a positive, and I hope they do, a positive diagnosis, it's still a lot to deal with. So just speaking to someone. A best friend's great, but they're also biased, right? Because they love you so much.

Elissa: Yes, professionals are better.

Erin: Yeah, and so I'm hearing them. Right. And sometimes you need that. Like I needed my best friend to say, "You're awesome and I love you, and I'll give you a

hug." But I also needed someone who was neutral to say, "In this situation, Erin, this is what you should do. You're in the wrong," or whatever it was. More neutral and professional.

Elissa: And there is something to be said about being given coping strategies and things that you can use so when these difficult times come up that you're ready and you know how to process these feelings in a healthy way.

Erin: Absolutely, that's why I love that you have this podcast because when I was going through this, I didn't even think to turn to podcasts. And I wish I had because now I find so many of them. No matter what stage you're in. If you're the caregiver, you're the patient, all of you have something very specific for people that have leukemia and lymphoma. And our caregivers, I mean that's phenomenal.

Elissa: Yeah, that patient education and caregiver education is just so important; and I think oftentimes it's an underutilized resource. So, we're really excited to be able to provide that to those people that are going through a diagnosis or a treatment or if they're watching their loved one go through it.

Now you took all of your experiences and then in 2020 you published your first book called, *Badass Advocate: Becoming the Champion Your Loved One Deserves*. I love that name. Now in the book, you shared eight strategies for advocating for a patient who is either homebound or hospitalized; and through your book and website, you share valuable information with the goal of empowering patient advocates to get their loved one the care that they deserve.

So, tell us a little bit about your book. What are some of the strategies of being a great patient advocate?

Erin: Yeah, and let me start by saying that the title was almost a joke, I should say, play on words. I did not feel like a badass advocate, so let me just make that clear to anyone who's like, "Okay, I'm not a badass advocate." But the point is, is that you can

be one. And with some simple and effective tools, you really can learn how to advocate.

And this goes back to what we were just talking about with all of you having this podcast and all the other podcasts out there. Why not learn from people who have been there, and what an advantage you can have over someone who was maybe more naïve, like when I was 20 and had no idea.

Elissa: Somebody's got to do it first.

Erin: Yeah, so learn from us. Do better. That's what I say.

Elissa: Exactly.

Erin: You could be way better than I was.

So, to share some of the ideas in the book, number one that I say is build a support team. And we already kind of talked about that a little bit, but you can't do it alone; and you shouldn't do it alone. And I know I've gotten some questions from people that say, "But I am the only child, and I'm taking care of my parent" or "This is my spouse, and they don't have any family. I don't have any family" or maybe "that don't live close by."

That doesn't mean you can't tap into your community and have them take care of even small tasks that can be taken off your lap, and you don't have to worry about. Even those little things like taking the dog for a walk or helping to schedule an appointment with the doctor or, "Hey, can you just drive them to this doctor's appointment because I have an important meeting that Friday." They're little things that others will be happy to do. Most of them don't know how they can help, but they want to help.

Elissa: Right. And it's good to be specific with people with how you want them to help because a lot of people say, "Yeah, let me know what I can do?" And the patient

advocate has friends, children, and neighbors, they can help. So it's really kind of looking beyond your family to find that support.

Erin: Yes. There's even people in the community. Like if you belong to any charity or if you belong to a church. My sister had some church ladies who she didn't know come and sit by her bed when we had, all had to go to work, just to keep her occupied. And so, if she needed anything, she had someone by her bed. Now she didn't know them. We didn't know them, but they were so happy to volunteer and help a 47-year-old woman who was going through a tough time.

Lizette: Yeah, we all have these good intentions. We want to help, but it's true, we don't know how to. So, to even help us and empower us how to help a family is really a great point.

Erin: Yes. I think that is such a great point, just to be very specific.

The other thing that I talk a lot about is, and this comes from my training background, is asking strong questions. So, this is probably one of the most impactful things I talk about because if you are like how I used to be, I am not a natural question asker. Now I am, because I've been 20 years in the pharmaceutical industry, and I've learned that skill. It is a skill, by the way. Now, if you're like my husband, he asks questions at every turn. That is just not my personality. He's actually a great advocate naturally when it comes to asking questions. Right, I would not have been.

So, I share in the book how you can ask strong questions and really, it's simple. You can ask open-ended questions or close-ended questions. They fall in one of those two categories. An open-ended question starts with what, when, how, where. So basically, when you ask that type of question, you get the person that's listening to you to give you more information naturally. If you ask questions that start with is, do, are, they're going to give you short answers, unless if they're a talker. But not all physicians are talkers.

Elissa: Yes.

Erin: A lot of times they just don't have that kind of energy. They're much more clinical. Not all of them, but sometimes they're more clinical; and they will give you the answer that you are looking for, meaning yes or no.

So, if you want more information, make it open-ended; and you can get a lot more information out of someone that they maybe didn't even think to tell you, not because they're holding back, but they may not think that's important to you.

Elissa: Right. And you talked in your book, it was almost kind of guiding them to the answer with the yes or no question. Like you mentioned in your book about asking if the patient could go for a walk. And being more open-ended would allow them to think about what can the patient do and give you maybe a variety of things versus them saying, "Yeah, sure, they can walk," and having it close down right there.

Erin: Yes, that's called a leading question. So, we naturally do it as human beings, especially if you're intimidated by physicians or whoever you're speaking to. We do it out of a way to protect ourselves because we don't want to put them on the spot. So, we'll ask a close-ended question because we feel safe. I can ask this little question, and then they'll be in my nice little bubble. But if you ask them an open-ended question, you can get so much more information that's unsolicited. So, you give a great example.

When you talk about exercise, instead of saying, "Can they go for a walk?" Well, the answer may be yes, but they can also do 500 other things that you didn't ask about. So how about, what kind of exercise would be best for this patient? And then you could get a whole list of ideas.

Elissa: That's great. Now of all the strategies that you went over in the book, what was the most important to you personally?

Erin: So, I think the most important one, ooh, that's a good question. I'm kind of between two. I will say to me personally, it was the things that I did for my sister. And so, I talk about sometimes we're so busy talking about the disease and thinking about the disease and fighting for the disease that we kind of forget about the patient.

Elissa: Right.

Erin: And we forget that there's a human there that is scared, and they're worried, and they're freaked out and I equate it to when you look at the movies and the one person's in slow-mo and everyone's running around at like high speed. I would imagine that is what it feels like sometimes. You can maybe tell me, but because everyone's talking and doing all these things, and sometimes you're forgotten, that you're a human being that's laying there and needs the mental support and emotional support.

Elissa: There were two things that stuck out to me in your book and in your experience. One when you talked to your mom separately from your sister about her treatment. And then, two, when you talked about staying calm in front of your sister like when the heart rate monitor went up and her pulse started racing. And having that calmness in front of your sister so that she would, hopefully, stay calm.

Erin: Yeah. I think there's a real lesson there, the first one that you mentioned, because we did it to both my father and my sister. I mean hello. Learn from your lessons. We did it twice, but we kind of excluded them unintentionally; that was not our intention, but it happens. Especially when you have a patient that's severely ill. They're at the point where they are not asking the questions, or they're not as engaged because they feel really crummy.

And it happened with my sister where my mom and I were talking about something about her care, and my mom mentioned to my sister, and I had mentioned to my sister, and then my sister was like, "Wait a minute, you two are talking about me behind my back." And, of course, we weren't saying anything bad about my sister, but

she realized we were excluding her from a conversation. She's like, "Wait a minute, I'm a grown woman; and I need to be a part of this conversation."

So that can happen unintentionally because there is so much going on. I think the key is just letting the patient know up front there are times where maybe you're sleeping or you're going to be on medication that makes you a little woozy. We may have conversations that you may not be present for. It's just honesty, but our best intention is to always include you. So, if we do that, we're sorry, but we will make sure that we come back to you. That's our goal is to always come back to you and include you because it is your health. It's your body.

Elissa: Right. Yeah, that's really important. And then how did you end up staying calm and emotionally stable while you were around your sister?

Erin: My goal always was to put on a happy face for my sister, even though I had severe anxiety and would cry at home. But I never want to come in there being sad and depressed because it was hard enough on her. Can you imagine? I mean we've all gone through this, even if something minor. Like you hurt your toe and maybe you're bleeding, and someone comes in. They're like, "Oh, it looks terrible." We're like, "What?" Then you think your toe has fallen off. But really if they said, "You'll be all right, you'll be all right," and they're calm, then you can be like, "Okay, it's just my toe. I'll be okay."

So really you need to do that for the patient because it's way more severe than a bloody toe. So, if you can be calm and as happy as possible, even though it's really hard and also empathetic, it's not like you have to smile all the time. Sometimes they need a serious face and for someone to feel the pain with them, you have to kind of read the patient, have that emotional intelligence, right?

I think for me, when my sister had that incident, so basically what happened was her blood pressure randomly just shot up; and she wasn't doing anything. She was lying in bed. I was working. She was sleeping at the hospital. And it went, I think it was to

180. It was something crazy. Now my sister and I typically both have very low blood pressure, like 106/80 or 60 or something. We're very low. So, for it to go to 180 was insane, and I could see the panic in her face.

And I understand that is really scary, so I wanted to help her, but I want to stay calm. And it was all because if I get her more upset, imagine what's going to happen. That's all I could think about was what's best for her, and I think as patient advocates, it's almost like the number one rule is what's best for them? Your focus is them, not you, until you're not with them. Then you can focus on you because you do have to take care of yourself, and that's really important as well.

Elissa: Definitely. That makes me think of when I was in the hospital, my parents lived four hours away, so they would come visit me during the week, go home during the weekends, and they would get their emotional support at home.

So, they would come in to see me, be strong, be ready to do whatever needed to be done. And I appreciated that, that I knew that they were getting their emotional support elsewhere and not trying to get it from me.

Erin: 100%.

Elissa: And I think that's really important.

Erin: And that goes back #1, the support team. So that's why you need more than one person supporting you because that caregiver is going to get burnout. We've all heard of caregiver fatigue or burnout. If you're doing it all on your own, of course, it's bound to happen. But if you have people that can come in and kind of pinch hit for you, then you can get that mental break.

In fact, I just was, posted something on social media about giving patient care instructions. If you need a break, you can create instructions ahead of time, maybe when the patient's sleeping, when you have some downtime, which I know isn't a lot

for caregivers. But so, kind of strategize and write down instructions on everything and anything someone would need to know to take over your spot.

On my website, I have a template to help guide you because you may not think of certain things; and that's fine. But that way, and we use this. When someone comes into support, you can go, "Here's everything you need to know. Take five minutes to read it, and then you have it with you, and it's all printed out. And I can go and run to Target or go have lunch with my girlfriends and have a break.

Elissa: Yeah, that's great. Now with all of these experiences, and you almost kind of reinvented the wheel for yourself with how to be a good patient advocate, what prompted you then to write a book and share these strategies that you learned with other people?

Erin: So, when my sister was in the hospital, she had some physicians that we just loved, and we would talk to them when they would come in. And I said to one of them, "You know, I feel like, as a trainer, I could maybe train people on how to advocate for their loved one."

And the reason why is because I had some nurses make comments. One nurse asked me if I was a physician or a nurse; and it was because of the questions that I was asking. It's not because I'm super smart. I'm of average intelligence. But just because I was asking the right questions, and they sounded like educated questions, she thought I knew more than I probably do.

But I was also asking questions to everyone. So, I was understanding about my sister's disease when I went into it not knowing anything about bronchiolitis obliterans. I never even heard that word before.

So, because of comments that were made to me, I realized I think I could teach other families who are thrown into this and have never been here before, I could teach them how to come in and do what I'm doing because what I'm doing isn't hard. Like I said,

"I'm no Einstein." It's just having these skills that I've built over time that I can easily share. I trained my sales reps on half of these. Not all of them because they don't pertain to pharmaceutical sales completely, but some of them do. And I could teach people how to do it, and then they can go into the situation more prepared and hopefully the whole goal is getting your loved one the best care possible.

I cannot help you cure them. If I did, my sister would be alive today. I would have figured that out. I can't do that. But when my sister passed away, I felt like, yes, I am devastated; but at least I did the most I could at the time to care for her. And she knew that and she told me that, and I have peace because of that.

Lizette: Yeah, I mean these organizational skills that you're providing to people in your templates I think are very important because when you're a patient advocate, when you're a caregiver, you do get to a point where you're so fatigued that it's not coming to you naturally anymore. You're trying to make it day to day. So, I think this is very important tool and I thank you for doing that.

Erin: Yeah, I agree with you, you get on autopilot and it's, I think the number one word that I'd use to describe a caregiver or even patient advocates is overwhelmed. You're overwhelmed by the disease. You're overwhelmed with the knowledge that your loved one is ill. Whether it's curable or not, it's still overwhelming. As the patient, you're probably overwhelmed too. And all of the medical jargon is just a lot coming at you. How do you make sense of it all and actually fight for your loved one? So, I'm hoping that what I put out in the world at least helps to ease it and make it a little bit easier.

I think the other thing we did that I'll share is that we recorded conversations, and that makes life easier too. So, this is the tip, this is why I struggled with your question earlier because my favorite thing is what I did for my sister because it's my memories, and that's very personal to me, things that I feel good about and that helped me have that peace.

But other people's favorites is when I shared that we recorded conversations. And what I mean is when you go into a doctor's office or when you're in the hospital and you're the patient, and I've been the patient for fertility, so I'm going to refer to my experience as a fertility patient. I remember going to the fertility doctor, and I was the one there. My husband wasn't able to be there, and the doctor gave me all of this information about fertility, and he said the first, probably few sentences, and I checked out. I couldn't tell you the rest of what he said probably for that 30-minute meeting because I was overwhelmed, I was in my head, I was thinking about pregnancy and what I'd been through.

And I imagine when you have a cancer diagnosis, that would be similar or even worse, right, because that's scary. And so, what is the worst thing that happens is you walk out of that meeting going, "What the heck just happened?" And I don't even know what I'm doing next.

So even if you're halfway through your journey or wherever you are, if you start recording conversations with physicians today, it can still be beneficial. So, what we did is I realized, this is a good idea because I lived halfway across the United States, and I was missing out on these conversations. And I wanted to know what the doctor said, not someone else's interpretation of that conversation but what was truly said. And so, I said to my sister when she was a little bit healthier, why don't next time you and mom go to the doctor, can you ask him if you can record the conversation on your cell phone. Everyone has a smartphone these days. It comes with a recorder. And he was totally cool with it.

And we did it from that day on, and when my sister went by herself, she recorded. If someone was with her, it was their responsibility. And then we shared that recording just within our little family support team unit, and we had some friends in there too. So, there's probably about less than ten of us. And that's with my sister's permission that we shared it, so she knew that was going on. So, make sure that you had the patient's permission and whoever you're recording, the physician, nurse. You have to

ask them first. You can't just start recording people's conversations. That's just not ethical.

And the point is not to catch them in anything, but it's for later on when you have questions and you say, "I don't remember what his response or her response was for this, you can go back and listen. And if you share with someone who wasn't there, we also realized we all picked up on different things because we have different personalities. So, we may have a follow-up question that my brother thought of that I never would have thought of or my mom wouldn't have thought of. But guess what, next time we see the doctor, now we have a question, or we can call them and say, "This is a question we didn't get to ask." So, there's so many different ways you can use it. I just think that's one of the best things that we did that was really helpful.

Edith: That's such a great tip. In your book, you identified various duties within the support team. What kind of duties does a patient advocate have and how is it important to designate people to do very specific things?

Erin: Yeah, so I think I have what, about eight or nine? I kind of forget how many there are. But I will tell you the reason why I designated different duties or jobs is because, again, going back to that support team idea, it's just too much for one person. And I don't know if people realize what they can delegate, that they can take off their shoulders because there's lots of smaller things that are important. And when I say small, it doesn't mean they're not important. It just means they don't take as much energy and time; and you can take that off your plate. You don't need to do that.

So, for example, this all came about because I wanted to make my sister laugh. I'll be honest. That's all that it came down to because she was struggling emotionally which I think you can understand that. So, I started to call myself the VP of Communication, totally as a joke because I told her and my mom and my brother that I would be the communication between me and the rest of my crazy family.

Now remember I told you I grew up with a big family, so we are inundated with tons of love, and it's great, but it's overwhelming as the patient and the caregiver, and sometimes you're exhausted and you don't want to email someone or text someone. You're just like in your bubble.

But I wasn't in their world. I was in Dallas, Texas, and even though I was having anxiety, I wasn't taking care of someone else besides my two-year-old. But when he was asleep, I could text people and email people and give them updates when they needed it.

So that's really how it started. That is a fantastic assignment for someone who doesn't live close by but wants to be involved. You do not need to live down the street to be the VP of Communications for your loved one. You can be the point person, and it can be a friend too, by the way. My best friend who's the three-time breast cancer survivor, I had been her VP of Communications. I think it was her second or third time, I forget, I guess it was her third because I came up with this idea; and I was like, "Listen, all of your friends, give them my number. If your mom wants to be the person for the family members, I get that because they know her, they trust her, but I'll take all of your friends." So, it can really be anyone that handles that, and then it takes the burden off of them.

Now the caveat is you still let them text the loved one and say, "I love you. I know you have chemo tomorrow. You rock. You're going to kick cancer's ass" – all that good stuff. But they don't have to respond, and you kind of communicate that out.

Elissa: And there were other duties, like organizing the meal train and organizing the medications and things like that, right?

Erin: Yeah, and the meal train one, again, easy, right? Your neighbor can do that. Why does someone who's a caregiver have to organize meals? That should be the last thing you're worrying about. Medications, now a caregiver most likely will be handling medications. The reason why I separated that one out is because I would advocate if

the patient is on a lot of different medications, I would say that you probably should have a backup and maybe two because there is going to be a time that you want to go out to dinner with your friends, and you need a mental break or you need to go to work or whatever it is. But your loved one still needs their medication on time. And if that's the situation you're in, then having a backup will allow you to do that in peace and not be like, "I've got to get home. They need their dosing, and I know they're not going to wake up in time," or whatever it is.

The other one that I love is the Director of Delight. By the way, I didn't come up with all these terms when my sister was ill. When I was writing the book, I was like, we kind of all had our little job; and we didn't realize it. We didn't put a term to it, but now I'm giving it to you so you can be better than we were.

So, the Director of Delight really reminded me of my cousin Jenny. And I hope, we all have someone like this in our life. She is a ray of sunshine. I would say there's probably not one person in the world that doesn't like you. She's so sweet and kind and easy going. And she would fly down from Philadelphia, and she and my sister grew up together, close in age. They were best friends, and it's like she would bring a rainbow just by her entering the room.

And patients need that and so do their caregivers and so do their family because when you're in it day in and day out, it wears on you. And you're scared or you're exhausted and you're overwhelmed. And to have someone who has fresh legs come in and, she would take my nieces out and take them to ice cream. Well, do you think the rest of us were worried about ice cream? No, but the kids need that. We were worried about getting my sister the treatment she needed; but her children needed attention. And so not that they were completely neglected. I don't want to paint that picture, but-

Elissa: Right.

Erin: -to have this person come in and they can be like this fun and shiny object that's like, "Yeah, the party's here." So, I think if you have someone like that in your

life, ask them to be that. And they don't have to be there every day. But however often you need it, the patient and the family.

Elissa: Yeah, I think we all need somebody like that in our lives to just brighten up the day sometimes.

Erin: Yes, especially during COVID, right?

Elissa: Right. Yes.

Erin: We all need it now, but like who do I know? Yes, start thinking of you, of your friends.

Elissa: You're like somebody should come decorate my house, just to have some fun.

Erin: Spice things up.

Elissa: Unicorns.

Erin: That's right, unicorns and rainbows.

Elissa: So how has your life changed since becoming a patient advocate?

Erin: Well, I'm focused a lot on patient advocacy, and I didn't expect my life to take this turn. But I really want to honor my sister. My sister was really involved in the lacrosse community, and at her funeral there were tons of young women and girls who came and honored her.

Now look, she's been my big sister my whole life, and I knew I was blessed. I always said it, and we told each other that, so I'm thankful that we had that communication. But I didn't always realize what an impact she had on other women's lives. I just thought that it was her girls and me; we were the special ones. But everyone was special, and they got a piece of my sister.



And so, after she passed away, I thought she has this amazing legacy, and what can I do to honor her and make sure that I'm giving something back to the world, just like she did. And it's a different way because I have different strengths and talents than she does. And so, I now truly believe that we all have something to give back to the world. So, it's really changed my outlook on life and just wanting to be that person that can honor her, and also it helps me with the grieving process because I will grieve the rest of my life for her.

Ironically, I just read an article last night about grieving. Everyone knows the five steps of grieving, right, the five stages. And it was interesting because the last one, it says now there's a new stage of grieving. I'm like, okay, I've got to read this article.

It was an awesome article by CNN Health, if anyone's interested. And they talked about denial, anger, bargaining, depression, acceptance. We all know those. If you're not familiar, those are the five. And then the last one they talked about was finding meaning. And I thought, oh, yeah, I get it because when I started focusing on patient advocacy and I wrote my book and now I have my website and I want to get into more speaking gigs and talking about how patients, teaching families how they can advocate for their patients, that keeps me going. And now I realize why like Moms Against Drunk Drivers, why they do what they do That's just an example. But anyone who's honoring their loved one, I get it. It really does help with the grieving process; and then you get to give back to the world and hopefully help someone else.

Elissa: Yeah, definitely.

Edith: And I'm sure right now you're helping someone listening to this podcast, so, yeah, it's a full circle.

Erin: I hope so.

Edith: On our patient podcast homepage, we have a quote that says, "After diagnosis comes hope." Based on your patient advocacy experience, what word would you choose to complete that sentence? "After a diagnosis comes?"

Erin: Ooh, that's good. After a diagnosis comes- I don't know if this one's going to be popular, but the first thing that comes to mind is a fight. And the reason why is because, the reason why I say I don't know if it's going to be a popular answer is because I do follow some cancer patient social medias and stuff because I think it's good for me to educate myself because I have not been a cancer patient. I think it's good for me to understand their perspective so I can improve my empathy. And I know they don't want to think that they're fighting or they're the warrior sometimes. Some people are okay with it; but I think of my sister, and she loved referring to herself as a warrior. And maybe it was the athlete in her.

And it's a fight for your health. It's not a fight against the doctor, but you're fighting against the disease. And I know it's a hard battle in so many ways, not just physically but also emotionally and mentally.

But just know that there should be and can be people there fighting alongside with you, and that's what patient advocacy is all about, having someone fight the good fight with you.

Elissa: That's so great. Well, thank you so much, Erin, for coming on with us today. It was really great to hear all about, some of these strategies and how really anybody in the support system of a patient could be part of the support team and a patient advocate. And so, I hope that those listening today will take a look at the resources and just see how to be a badass advocate. I absolutely love it, so thank you so very much for being with us today.

Erin: Thank you so much. Thank you for all that you do. I just love this organization. I'm doing the Night The Light.

Elissa: Oh, you're doing Light The Night! Yay!

Erin: So just a little plug for you guys. If you're not doing it and you're feeling good or you're a caregiver, an advocate, go do it and support this wonderful community.

Elissa: Wonderful. So, carry that gold lantern with pride.

Erin: That's right. That's right. Yes. Thank you so much.

Elissa: And 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. 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. 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. 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). You can also find caregiver support resources at [LLS.org/Caregiver](https://lls.org/Caregiver).

Lastly, if you'd like to get more information on Erin's book and the resources she shares to become a great patient advocate, go to www.badassadvocate.com. All of these links will be found in the show notes or at TheBloodline.org. Thank you again for listening. Be sure to subscribe to *The Bloodline* so you don't miss an episode. We look forward to having you join us next time.