

## THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

### ***Episode: 'Engaging with Loved Ones: A CaringBridge Story'***

#### **Description:**

Join us as we speak to lymphoma patient, Leona, her husband and caregiver, Howell, and Tia Newcomer, the CEO of CaringBridge®. In this episode, Leona and Howell discuss the benefits of utilizing patient and caregiver support resources like the online journaling site, CaringBridge, to communicate with loved ones after Leona's diagnosis. They were comforted that the site also afforded the opportunity for family members and friends to engage and give them support.

Tia then shares the mission of CaringBridge and how it has evolved into a community of over one million pages where patients and caregivers communicate their updates and needs with family members from diagnosis through survivorship.

#### **Transcript:**

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

**Jesse:** I'm Jesse.

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

**Elissa:** Today we will be speaking to Leona Newman, a lymphoma survivor; her husband and caregiver, Howell; and the CEO of CaringBridge, Tia Newcomer. Leona is the Patient and Professional Content Consultant at LLS. While working at LLS in her prior role as an Information Specialist in August of 2021, she was diagnosed with diffuse large B-cell lymphoma, a type of non-Hodgkin lymphoma. After six rounds of chemotherapy, she reached complete remission.

Leona's husband, Howell, served as her primary caregiver throughout her treatment. Married to Leona for 41 years with two adult children, he was tasked with supporting



Leona, managing her care, and communicating with loved ones who requested updates on her condition and treatment.

Tia joined the CaringBridge team in 2021 and ensures that all operations contribute towards the CaringBridge vision, a world where no one goes through a health journey alone. She is passionate about building on the 25-year CaringBridge legacy and leading the team in finding the next opportunities for growth that exponentially help more families with their health journeys.

Welcome Leona, Howell, and Tia.

**Howell Newman:** Thank you, it's good to be here.

**Tia Newcomer:** Thank you.

**Leona Newman:** Yes. Thank you for the opportunity to share my experience.

**Elissa:** So, Leona, we will start with you. Could you tell us about diffuse large B-cell lymphoma and what signs and symptoms led to your diagnosis?

**Leona:** My case was very interesting in the sense that I didn't have the typical enlarged lymph nodes externally that would give people an idea that something was going on. I had extreme fatigue and night sweats, which literally would wake me up at night. My pajamas and the linens would be soaked, and I really needed to get that taken care of. It was quite uncomfortable.

I got referred by my primary care physician to a hematologist oncologist, and it turned out that I was quite anemic at the time, and I was sent to the hospital for a blood transfusion. Subsequently, I was very anxious to start treatment because I knew I would feel better, and all the arrangements were made.

It was an interesting scenario for me to experience as an Information Specialist with The Leukemia & Lymphoma Society because I already knew what to expect from my treatment. I found it to be a double-edged sword. There were positives and

negatives. I knew I could go to LLS for accurate, up-to-date information and all kinds of support services, but I also knew questions to ask and maybe sometimes getting a little bit too much into the details. It comes down to really trusting my treatment team and all the people that went before me knowing that my treatment, which was R-CHOP, was a tried-and-true regimen for diffuse large B-cell lymphoma. And that's how it all started.

**Jesse:** Now this question is for Howell. What thoughts were going through your head when Leona was diagnosed with cancer? Not only did your wife now have cancer, but you also had to navigate your new role as a caregiver. Could you share what that experience was like?

**Howell:** So, the first time you hear the word cancer; it scares you a lot. I was scared when she went into the hospital even before cancer when she was so anemic that they had to give transfusions and they really weren't sure what was going on, but Leona was pretty sure she knew what the diagnosis was before we even spoke to the doctor. I had it in my brain that that was going to be the diagnosis, and it turned out she was correct. I was a little bit prepared, but it's still a shock and you're scared because cancer is scary, and you don't know what the outcomes are going to be.

Fortunately, Leona, because of her experience, knew the treatment methodologies and how successful they had been, and the doctor was also very reassuring that this was a tried-and-true methodology. And so, I felt a little better about it. Still always in the back of my mind that we don't know what's going to happen down the road.

I was like a mother hen in the beginning. I was constantly taking her temperature, checking her pulse ox (oxygen saturation in the blood), doing everything the doctor told me to do, making sure she had her medications right on time because they do scare you a little bit. They tell you that if her temperature hits a certain number, you have to get to the hospital immediately. I was vigilant to make sure that the minute her temperate went up half a degree she took Tylenol. Just those types of things to

make sure that we didn't have to go to the hospital or nothing worse was going to happen.

So that was my initial reaction. The other thing I was worried about was her going through chemotherapy. I had never experienced that with anybody. Fortunately, my parents never had that experience or no one in my family, so I wasn't sure what to expect. But after the first treatment, which she tolerated fairly well, I felt better about it, and she started feeling better so that was a big help.

**Jesse:** Absolutely.

**Lizette:** Yeah, now, Leona, you and I used to work together as Information Specialists.

**Leona:** Yes.

**Lizette:** So, you know that we know quite a bit about blood cancers. You knew about DLBCL [diffuse large B-cell lymphoma], the type of lymphoma you have. Your physician probably was not used to patients being so knowledgeable.

**Leona:** That's true. It was kind of funny when he confirmed the diagnosis, and I said, "Well, I'm going to have R-CHOP and my hair will fall out, but it's treatable and it's curable and about 60 to 70% of people are cured. So just going to move forward with this and do the best that I can with your help." But he was a tremendous support and a source of information, of course, as well.

**Lizette:** Yeah. Now did it make it more comfortable for you to get the diagnosis because I think Howell mentioned that you probably already knew the diagnosis or were thinking that that may be the diagnosis before they actually did diagnose you.

**Leona:** I had a suspicion, but it's always good to know what you're dealing with, to have the facts and to know what to expect. Even though I never had chemo, I just had a sense that I could manage it. I was just going to get through it, especially with

my excellent husband caregiver. I was fortunate to have the support of all my LLS colleagues, my family, my friends, a great medical team. I knew questions to ask. I knew about getting a second opinion. I had a lot of resources at my fingertips. So even though it was overwhelming and scary at times, I knew we were going to get through it.

**Lizette:** Was the doctor surprised at how much you knew?

**Leona:** Maybe a little.

**Howell:** Well, yes. I'm laughing only because after the doctor gave us the diagnosis and the prognosis and everything else, he said, "You know, you can get a second opinion." And I turned to him and said, "She is the second opinion. She knows as much about this as probably anybody." And she had done, obviously, the research before, but she had the knowledge before even walking in. So that's why we felt comfortable with him and his team and the treatment plan.

**Jesse:** Leona, as you know, friends and family often want to help when someone close to them is diagnosed with cancer. Personally, I know when my mother was diagnosed with leukemia, I wanted to do anything and everything to, obviously, help her and be there for her. Were you and Howell able to communicate your needs for help? And, if so, could you explain to our listeners how you did that?

**Leona:** Let me start by saying that my anemia was quite severe to the point where I was so fatigued that it was even hard to talk. Where normally you would welcome lots of calls from friends and family, I really wasn't up for it. We needed to figure out another way for Howell not to be inundated with calls, texts and emails and repeating the same information over and over. So, we had to figure out a solution to that, and that's how we did sign up for the CaringBridge website.

**Jesse:** Very good.



**Elissa:** And then not only do family and friends want to help but they also want updates. When I was going through my treatment for acute myeloid leukemia, or AML, I used CaringBridge and that's essentially an online journal to provide updates to loved ones.

Now, Tia, as the CEO for CaringBridge, could you tell us a little bit more about what it is and how it came about? It's commonly used for cancer updates. Was it always that way and can it be used for other things?

**Tia:** Yes. Thanks, Elissa, and first, Leona and Howell, thank you for sharing your story. It's near and dear to our hearts at CaringBridge and my own, so I just appreciate you guys being brave enough to come forward and share your story. So, thank you.

People like you are the reason why CaringBridge was founded in 1997. So, 25 years ago, our founder, Sona Mehring, had friends and family that were not going through a cancer journey; they had a preemie baby, Brigid, and she was only on this earth for a short nine days. And during that time, you can imagine the tremendous amount of community support, and need and desire to understand what was going on during that really hard time.

Sona was one of their good friends. They asked her to communicate out to their very large community and, by the second call, she was exhausted and thought to herself, there's got to be a better way. She's an entrepreneur, a woman of STEM, and she went down to her basement and coded the first CaringBridge.

And now, that one website has turned into over one million sites helping people communicate and really activate their community and supports when they're going through any health journey. Around 75% of those journeys are cancer related and the others are things from, again, premature babies, all the way to people who are injured suddenly, to other disease states. So, it is a tool for everyone, but we do find that cancer journeys tend to be the majority of what we support.

**Jesse:** Tia, can you explain why you felt CaringBridge is an important tool to use after a cancer diagnosis and going through treatment and beyond?

**Tia:** I think that feeling, and Leona and Howell, you brought it to life, there's that feeling of overwhelming I just need to focus on what we need to go do to get healthy. And then you have well-meaning and needed community that really wants to surround you and help you. And so, in that moment where there's a lot going on, CaringBridge can come in and help you in that one easy place in the time that you have and when you have it. It can be at any time. It could be sitting getting an infusion. It can be in that moment where you woke up in the middle of the night and just can't go back to sleep. It's that anytime, anywhere I can activate my community and relieve some of that stress that's going on as you're trying to get healthy.

One of the other things that we find is it's very hard when you're in the position, and, Howell, I'd love to know thoughts on this, and Leona, to ask for help. And what CaringBridge does is gives you that platform so it's a little less scary. You can type in, "Here's the help we need this week." We actually have a planner tool that allows you to ask for something as simple as a meal, all the way to maybe you need financial support through GoFundMe™ or other mechanisms. CaringBridge really takes away some of that barrier that is so hard to ask for help. And we know a lot of people need it, but it's very hard to ask for that.

**Elissa:** Now, Howell, there are certainly many resources out there to help patients and caregivers through a diagnosis, like CaringBridge, but also sites like Meal Train® and social media. How were you able to utilize these sites, and did you ever delegate sharing updates or arranging meals to your adult children or other family and friends, or did you just take it on yourself?

**Howell:** Kind of both. So, the CaringBridge I took on my own. It was actually Leona's suggestion when she was in the hospital. We really wanted to cut down

initially on people calling, emailing and texting and having to repeat the same story. So that was the initial start of it. It turned out to do a lot more than that for us.

To answer your question, we did have friends develop a Meal Train for us. I did not do that. So, two of our very dear friends set up a Meal Train for us. They asked us what days we would want something, and we chose a couple days during the week. And they went out and basically told the world. And they were telling a friend and they told a friend, and they told a friend. And the next thing we know, for six months we had meals twice a week. People were extremely generous. Usually, one meal lasted two or three nights for us. So, I didn't have to worry about that part.

The CaringBridge part, though, was a tremendous relief for me, not only to deflect all the phone calls and things, but it was also a way for us to manage our own narrative. We got to say what we wanted to say and to tell people what we wanted them to hear, to hear the truth from us. It wasn't rumors from other people or telephone tag from one person to the next. And it allowed us to communicate with a tremendous number of people at a time. I think at some point, we had well over 100 people that were responding to our information on CaringBridge.

It was also somewhat cathartic for me too. It allowed me kind of as a release to get out there and tell everybody the story, let everybody know how Leona's doing and how I was doing as well, even though that was a minor piece of it, but people did care which was nice. But in writing the history, it allowed me a lot of stress relief I felt, and it also gave us our own little formal record of everything happening from day one on.

That's something that you don't think about when you're doing it, but it's a tremendous help to be able to go back and say, "Okay, what happened last month? What exactly did the doctor say?" Because we put that in the document. So, we were able to maintain that going forward and kind of learn from ourselves even.

**Elissa:** Yeah. I love that CaringBridge is easy enough to write on there and be able to give those updates. It is cathartic to write it out, to some degree, and also it



creates almost a little community with your family and friends as well that they can comment and give encouragement to not only the patient but the caregiver and the family and all the loved ones that are reading it.

**Howell:** Yeah, I felt it was great too that not only my writing, but we'd come back and read what people posted on CaringBridge. We're very private people, so for us to do something, quote/unquote, "social media," is very unreal because we don't have any other social media accounts. So, it was a little unnerving from that point of view, but it was just a beautiful thing to be able to read all the things that people came back and said and all their good wishes and offer for assistance that sometimes we would follow up with if we needed to.

**Leona:** Yes. I just will add on that it was very heartwarming to read people's comments, words and wishes of support and tributes. And it makes a world of difference when you know everyone's behind you cheering you on.

**Jesse:** Absolutely.

**Tia:** Leona and Howell, I'd love to add that we actually did a study with the University of Minnesota and Mayo Clinic. Out of that study they looked at all the people that have been using CaringBridge over the years. We get about 45 million a year that come and interact, whether writing cathartically, like you said Howell, or interacting with those comments and giving that love back and support.

They found that for those that wrote 80 words, and that's not a lot if you think about it, 80 words or more a day, there was actual improved health outcomes and the healing effects of that support you're talking about from that engagement in the community contributed to, whether it be feeling more centered, grounded, stressless, as much as you can be. So, it's really interesting and good to hear you guys underscore that. That love coming back, and support really means a lot to the health and the outcomes.

**Howell:** Yeah. It was also interesting because, obviously, this was during the pandemic, so the world was somewhat shutdown. We had been shut down prior to her illness, so there really wasn't a lot of contact with people. This was almost a way for us to make contact with the world that we were missing just because of the pandemic, and this kind of doubled up on it.

**Leona:** I think we liked the flexibility that whenever we felt it was the right time to post an update, we could do it on our own schedule. There was no scheduled time; you could do it on your own.

**Lizette:** Yeah. Elissa had mentioned that. I know that while you were going through treatment, Elissa, you mentioned that you were too tired sometimes to-

**Elissa:** Yeah.

**Lizette:** -be able to post an update. I think it's great that when you can provide that update. Also something you said, Tia, that is very important. Knowing Leona and having worked with her, she is a giver and Howell is also a giver. And this CaringBridge really puts a platform out there for people to be able to ask for that help because not everybody is comfortable with asking for help. So, I think that's a really important piece of CaringBridge, that it allows you to ask for help a little bit easier. I don't know, Howell, if it was very easy to ask for help, but I know that we hear from a lot of patients and caregivers that it's not the easiest thing to do.

**Howell:** Yeah. As you said, we're not the type of people to usually ask for help. So, it was a little different from that point of view, but we also knew that we needed it. There was no way that I was going to be able to manage it on our own. Leona was way too weak in the beginning. So, for me to have to cook seven meals, seven nights a week was going to be impossible.

There were other things that people offered, to bring groceries or what have you. That was very helpful to us that I probably would not have reached out to people



individually to ask for help. But to do it on the platform or if somebody just said, "Hey, I just read your post. Is there something I can do to help?" that would then prompt me to go and reach out to them more than I probably would have.

**Elissa:** Lizette had mentioned that when I was writing on my CaringBridge page, a lot of times I was just very tired. People would be like, "Where's the update? What's going on?" And I'm like, "I'm just tired. I just want to sleep." And it's really hard. For me I didn't have an in-house caregiver when I was going through treatment, and I'm sure a lot of our patients listening didn't have a caregiver. My caregivers were my parents who lived four hours away. Sometimes I wish I would've just asked them to do updates because, of course, they were keeping updated all the time. They were visiting my city and staying with me on chemo weeks and when I was in the hospital.

I know that Howell has used CaringBridge quite a lot. Is it easy in general for caregivers to get on and do these updates for patients?

**Howell:** It could not have been easier. I grew up in the technology area. I worked in technology for over 30 years, and I've seen some really bad technology displayed. CaringBridge was fantastic. It was so easy to set up. When Leona said to me, "Go set up a CaringBridge page," I didn't really know anything about it. I had read one CaringBridge page in my life.

She was in the hospital. I went home, went onto the website. Within ten minutes I had a page up. It was that simple. You can do all sorts of things. We didn't even use all the capabilities that are available. We chose not to post pictures, but people certainly can. Ours was just text. But I know there are other capabilities that the tool has and it's, I said, just very simple for us and also very simple for the readers to use because all I did was just send a note out to people saying, "Here's the link. Go and send to other people, whoever wants to see it." And the next thing you know we had 50, 60, 70, 80 people just looking at the site. Nobody had any issues to my knowledge.



**Elissa:** That's great. Now, Tia, is the site capable of having multiple people give updates on there or is it just the single person that signs on and creates the account to do the updates?

**Tia:** Great question. We do. We call it coauthor and at set up or any time after, you can add as many coauthors as you want. We actually see more engagement and more communication. Like you said, Elissa, sometimes patients want to communicate and then sometimes the family caregiver, sometimes a sibling that want to help in that communication.

A lot of people come off Facebook into CaringBridge, as an example, because it's just a little bit more controlled and you have that ability to have multiple people communicate on your behalf.

**Jesse:** Tia, I had a friend that's on CaringBridge and her daughter is updating her treatments with her AML. Then one of my Facebook friends also created an account on CaringBridge. When I signed into CaringBridge, I noticed they were both on there and I didn't have to do anything. How does that work logistically?

**Tia:** It's a technology magic. Facebook and other social media link to that CaringBridge site. So, for example after you make your CaringBridge site, you can choose to share it via Facebook or other social media platforms or texting as an example so that your community can interact with your CaringBridge site however they want. And you can broaden that community, or you can keep it tighter.

**Jesse:** Yeah. I just wanted to share that. I thought it was really interesting, and I liked it.

**Tia:** Thanks.

**Jesse:** Howell and Leona, you had touched on this earlier in the conversation. How is using CaringBridge helpful to you both during treatment?



**Leona:** As we said, keeping family, friends, and colleagues up to date in a very easy way on our schedule at our convenience, was the best part and relieving us from the constant calls, texts, and emails.

**Jesse:** Yes.

**Howell:** Yeah, it was that and going back and having that formal record of previous treatments or previous weeks. We didn't post every day. Probably a couple times a week I would post. That led us to go back and see what did we post last week? What did we post last month? What were the doctors' numbers last time versus now? So, we had a record of what went on so we could always go back and look at it as well.

**Elissa:** Leona, you mentioned something that I'd like to touch on. CaringBridge helped relieve the individual texts and emails. Everybody that knows about your cancer wants an update on how things are going. You often get bombarded with multiple texts, emails and phone calls. It's hard to give individual updates versus just going on this and writing out all of the updates and say, "Hey, here's a link. You can stay updated. Of course, still check in and see how things are because we want our family friends to just be present, right? But-

**Leona:** Exactly.

**Elissa:** -for updates. This is really nice.

**Leona:** Absolutely. I would highly recommend it.

**Howell:** Yeah. The first post that we put out there was before her actual diagnosis when she was still in the hospital with severe anemia.

**Elissa:** Oh!

**Howell:** We had basically only told our siblings and children that she was in the hospital because we didn't really know exactly what it was yet. And we told them not to tell anybody. That didn't work very well.

**Elissa:** Usually it doesn't.

**Howell:** The next thing we know my son was getting texts from relatives saying, "What's going on with your mom?" And so that's when we decided to start the CaringBridge. And the first piece of information I put in CaringBridge was, "Please do not email, call, or text us. We will post here regularly. This is where your official information will come from."

**Leona:** But he said it in a nice way. Don't worry.

**Howell:** In a nice way.

**Leona:** We just wanted to have the facts because people start to speculate and get out of control. We wanted to just stick with the facts.

**Jesse:** Yeah.

**Howell:** Yes. They paid attention and was very helpful to us to be able to manage what we were dealing with, especially in the beginning.

**Elissa:** That's good. Now how often were you putting updates on there?

**Howell:** In the beginning, I would say every day when she was in the hospital; and when she first came home, probably every day or every other day. Later it got down to maybe once a week or twice a week. Once she started recovering and handling the chemo so well, we would put up an update maybe once or twice a week at that point.

**Tia:** We find that it's very similar to what a lot of people write at the beginning. It's managing the influx of well-meaning support and updates. There's a point within your journey that you're looking back at information in that moment that you were recording and/or updating. We find a lot of people that come back every year and say, "It's been one more year cancer free. And here's what we're doing. Here's the update." And so, it's a bit of a memorialization. People printed it out, "I'm a survivor of ten years," and they'll print that out as a memorialization of that journey.



It's that cathartic piece that a lot of people tell us is very helpful not only within the journey but after and being able to celebrate getting through those journeys.

**Elissa:** Oh, that's wonderful! I hadn't heard that people were utilizing old posts to celebrate. That's so beautiful.

**Jesse:** Yes.

**Elissa:** I love it. Our final question to all three of you. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your experiences as a patient, caregiver, and then CEO of CaringBridge, what would each of you say to patients and their families to give them hope after a diagnosis of cancer?

**Leona:** Well, I'll go first. I will just say that the science is changing every day. We're making so many improvements in treatments and managing side effects that you should always have hope and just get the best medical care you can, trust your team, and then rally your family, friends, and colleagues to support you through it all.

**Howell:** Yeah, as a caregiver, I would say pretty much the same thing. I mean there always has to be hope. Hope will help you get better. Hope will help you heal. You have to look to the future and believe the science. That to me is the important thing and find physicians and organizations that are specific to your diagnosis and trust the history of what they've done and the research that's going on because even if there's not something today, that doesn't mean there won't be something tomorrow that's going to help you.

**Tia:** I'm going to give two points of view. One as a caregiver; we all will be or have been a caregiver at some point in our life. Personally, my husband is a two-time cancer survivor.

**Elissa:** Oh!



**Tia:** Our family motto comes from him at the age of 17 with his first round of cancer. The quote is, "What you do today is important because you exchange a day of your life for it." I share that because there are so many people when you get this diagnoses that are doing really amazing things, exchanging a day of their life for advancing science, seeking out treatments, supporting families that are going through health journeys. And knowing that you have that community around you that is ready and willing to support you, is probably the biggest piece.

And, of course, as a CEO of CaringBridge, the other hat I'm going to talk to is don't be afraid to ask for help. Don't be afraid to rally that community behind you because it will lift you up in more ways than you can ever imagine. And that's what my team and I come to work every day. It's not even work really. We're seeking to really help more people connect and rally that community and support.

**Jesse:** Well said.

**Elissa:** Thank you so very much, Leona, Howell, Tia, for joining us today and sharing all about your cancer journey, caregiver journey, and then, of course, all about CaringBridge and how it can really benefit not only the patients and the caregivers but all the families, the loved ones, as well, to keep everybody updated through a cancer diagnosis and also bring people together.

So, thank you so much for sharing with us today. For our listeners, we will have links in the Show Notes and at the end of this episode to check out CaringBridge and then, of course, our resources that LLS has for you. Thank you all again.

**Leona:** Thank you.

**Howell:** Thank you.

**Tia:** Thanks.





**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 could be found in the Show Notes or at [TheBloodline.org](http://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.

In addition to the survey, we are excited to introduce our brand-new 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. Join for free today at [TheBloodline.org/SubscriberLounge](http://TheBloodline.org/SubscriberLounge).

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](http://LLS.org/PatientSupport). You can find information about CaringBridge or register at [www.CaringBridge.org](http://www.CaringBridge.org). All of these links will be found in the Show Notes or at [TheBloodline.org](http://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.