# THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

***Episode: 'Joy, Hope, and Healing Beyond a Cancer Diagnosis'***

## Description:

In this episode, we speak with Dianne Callahan, four-time cancer survivor, best-selling author, speaker, and patient advocate. Dianne shares her experiences with non-Hodgkin lymphoma and breast cancer, stem cell transplant, and survivorship while highlighting the importance of advocacy, joy, and intention in life after diagnosis. From her work with fundraising campaigns to legislative advocacy on Capitol Hill, Dianne offers inspiring insights on resilience, hope, and the power of living intentionally.

## Transcript:

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

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

**Elissa:** Today, we will be speaking to Dianne Callahan, a four-time cancer survivor, international best-selling author, keynote speaker, and legislative patient advocate. Dianne was first diagnosed with Stage IV follicular lymphoma and diffuse large B-cell non-Hodgkin lymphoma in 2007. She later participated in a clinical trial and then underwent a stem cell transplant in 2013. Unfortunately, in 2022, she faced cancer again when she was diagnosed with breast cancer. After her first diagnosis, she turned her attention to fundraising and volunteer leadership, participating in multiple LLS fundraising campaigns and also becoming a peer-to-peer support volunteer and, patient advocate for public policy. She has also written several books to share insights and experiences from navigating cancer. Welcome, Dianne.

**Dianne Callahan:** Hi, thank you for having me.

**Elissa:** Thank you for being here. So, let's start with your diagnoses of follicular lymphoma and diffuse large B-cell lymphoma, which are both non-Hodgkin lymphomas. Were you diagnosed with both of those at the same time?

**Dianne:** Yes, basically. What actually happened was, weirdly enough, in 2005, I started having some weird autoimmune stuff like big chunks of my hair fell out, and I was exhausted and all this stuff. And so, they were trying to figure out what was wrong with me; and they had me do a bone marrow biopsy, and they said it looked like leukemia but wasn't acting like leukemia.

So, we just did watch and wait; and I went back to work and everything seemed pretty fine. And then it was 2007 when what happened, was this, it looks like follicular, I think, transformed or one of them transformed. See, I don't have all the science behind it. But it was becoming a monster like so fast. The first symptoms were on Memorial Day weekend 2007 and I started having pain in my bones. But it was moving all around. It would be in my ribs, and then it would be in my pelvis, and then it would be in my chest; and so, my doctor and I were like, "What the heck is wrong with me?"

And then I said, "I also have this lump on my neck," and he was like, "Oh, we're going to need to get that biopsied." Well, by the time I went in for the pre-op appointment for the biopsy surgery, it had gotten so bad that I was in a wheelchair because it was too painful to walk. It hurt to breathe. It was bad.

And so went to the preop appointment, and I was shaking as I was standing to get my weight and all the things. And the nurse finally said, "You need to go to the ER." And I'm like, "When?" And she's like, "Right now." I said, "Well, I thought I was supposed to be here doing this pre-op thing." And she said, "No. You need to go to the ER." So, I sat back in the wheelchair. My sister, Julie, went to push me out of the room and we went to the ER, and the doctor there did a lot of blood work to test. And he said, "We're going to need to admit you because this isn't looking right."

So, I get admitted into the hospital; and they did the biopsy as an inpatient, and I was still there when it was time- I had had an appointment set up with an oncologist to review the biopsy results, right? The day of that appointment came, and I was still in the hospital. The nurse came in and said, "I'm going to call your oncologist downstairs and tell him you're up here and ask him to come see you inpatient." And so, she made that call, and when she came back in to tell me the results, the ER doctor had come up because I guess there's something called chart stalking; and he had like looked at my chart, and he's like, "Wait a minute, it's like ten days later. Why is she still here?" So, he walked into the room at the exact moment that the nurse came in and said, "The oncologist said he's not going to come up and see you, but when you get out, to call his office and set up an appointment to see him then."  And so, the ER doctor, I could see this look of anger and frustration on his face, like shock.  And he said, "Excuse me. Would you mind if I called a different oncologist and asked him to come up and see you today?"  I said, "No, that-" You know, I was on a lot of morphine.  I was like, "Sure."

**Elissa:** Yeah.

**Dianne:** The more the merrier.  It's a party.  Within an hour, another oncologist came up, and he looked at all my results, and he said, "We need to do a bone marrow biopsy." And so, what happened was when he took the bone marrow out of my body, that is usually this rich, vibrant, luscious red, right?  Mine was a milky pink because it was so compromised with cancer.  And so, he said, "We're going to send this up and get things typed and everything.  As soon as we get the results, we're starting you on chemo tonight."

And so, he's been my doctor for 18 years.  He later told me the day that we met, he said, "You were at death's door, and you didn't have another 24 hours."  So, think about it.  If that ER doctor had not come upstairs, I would have gone home in a body bag, not gone home healthy enough to call the other oncologist.  So, it was crazy.  So, we started a very aggressive, chemo regimen called R-CHOP and using Rituxan®, which, he researcher that found it was funded by LLS and saved my life.

**Holly:** Now, Dianne, we mentioned in the introduction that you later participated in a clinical trial and then underwent a stem cell transplant.  Had you been in remission for a few years and then relapsed?

**Dianne:** Yes.  So, here's what happened.  The day that I met Dr. Ferrell, I asked him three questions.  I said, "Are you good at what you do?"  And he said, "Yes, I am."  Okay. I said, "Are you ready to be aggressive," because nobody got time for this, right?  I need to get this done and move on, and he said, "Yes."  And I said, "And do you actually care if I live or die?"  And he said, "Absolutely yes."  So, we had been talking about being very aggressive.

So, what he wanted me to do was go straight into an autologous stem cell transplant using my own cells.  And by the time I got through six months of this heavy R-CHOP and got into remission, I needed to get back to work.  I mean, the last month of my medical "vacation," so to speak, I worked for a school district; and those days were actually donated by my colleagues so I could still stay on medical leave. Yeah. So, I was like, "I've got to get back to work. I've got to get back to life."

So the other story is I had started dating this wonderful man in April of that year. So, by the time I got in the hospital, we hadn't even been together three months. And he came to the hospital every night to see me; and on the night we found out what it was, he walked in and I'm already hooked up to all the chemo, I said, "You should run. You are free to go," because he had two kids and he was looking for someone to help him finish raising his two kids and to have fun with. I'm like, "I'm not sure I can make those commitments at this point." And in my head, I was like, and I don't want you to ghost me three months into this, whatever this is, what it's going to look like. And he said to me, he said, "When God gives you a gift, you don't give it back." And then he said, "I already know I want to spend the rest of my life taking care of you. So, even though I wasn't ready to do this here, will you marry me?"

**Holly:** Oh!

**Elissa:** Oh, my gosh.

**Dianne:** Then I said, "Yes." And if he were here on the podcast, he would say, "And she was on a lot of morphine, so I didn't know if she was going to remember it." And I did.

**Holly:** Either way, it was a yes.

**Dianne:** It was a yes, and so as I said, Dr. Farrell wanted me to go straight into the autologous transplant; and I was like, "I need a break. I need to get married. I need something." And so, he said, "Okay, we'll put it in our back pocket." He thought I would get two years of remission. I actually got four years of remission.

**Elissa:** Oh, okay.

**Dianne:** And in that time, I got married, I got to be a bonus mom to these two great kids. We got involved with LLS by walking in Light The Night, and there's more to tell about that. And then the Executive Director of my local Southern California chapter called me up and said, "We need you to switch jobs and come work for us." And I'm like, "I'm really good at my job. I speak nationally. and I have to triple my commute." On paper, it sounded crazy, but I knew it was probably the right thing to do, to take this experience and turn it into helping millions of people. So, I said yes again; and I started working for LLS in 2009.

And so, when the relapse happened, I was on staff for LLS; and that was when we started getting ready for the autologous stem cell transplant using my own cells. And that's when I was in the clinical trial because they had this idea that using a radioimmunotherapy (RIT) drug called Zevalin® would increase the efficacy of using your own cells in the transplant.

And the funniest thing about it, the doctor who was running this clinical trial, he looked like the lovechild of Benjamin Franklin and Doc from *Back to the Future*. Can you picture it? That's who my doctor was. And so, we're in there, and I had to do a test dose of the Zevalin, and he turns around and the needle I kid you not, is like 6 to 8 inches, long. Because it has to be so far away from him because it contains radioactive material. And I'm like, "Well, good for you. You're putting that into me."

And so, he starts putting it into my arm, and that stuff burns, let me just tell you. And he looks at my husband, and he says, "Hey, so what do you drive?" And I'm like, "Are you guys having the car conversation right now here?" And so, Chuck's like, "Well, I drive a Dodge Durango; and he said, "That's good. Is that the one with the three rows of seats, you know, the way back." And Chuck said, "Yeah." He said, "Okay, good, because she's going to have to sit in the way back. You guys have to keep the windows open; and when you get home, I know you don't have little kids, but she can't be around children or pets, so you're going to have to keep them separate. And she needs to sleep in a separate room because she's going to be a little radioactive." And we're like, "What?"

So, I was a little radioactive. I did well with the test, and so we did the large dose. But as my oncologist says, "The whole thing was an epic fail."

**Elissa:** Oh!

**Dianne:** It didn't work at all. So, that was in February of 2012; and within four or five months, the cancer just raging back. Typically, it likes to make tumors in your lymph nodes. Right, it occupies your lymph nodes and takes over. This time it was just making its own tumors throughout my body. It's like, "No, we'll just like grow here and we'll grow there." And we were like, "Oh, my God, this is like coming back gangbusters."

So, then we had to search for an unrelated donor because, check this out, I have four siblings, two brothers and two sisters, full siblings, same parents. Normally, each full-blooded sibling has about a 25% chance of being a match. So, I thought 25 times 4 is 100, I'm good. And not one of those people's a match for me.

**Elissa:** Wow.

**Dianne:** Which, gave rise to all the jokes about how I must have been adopted, which is fine. So, I was so blessed because I'm 100% Norwegian. And so, we had all confidence that we would find a donor on the Be The Match registry. And we did. We fairly quickly found a great match because there's, a high preponderance of Northern Europeans on the registry that would be a good match for me. And so, that's when my heart started to break because I realized if I were some mix of ethnicities, I probably would not have found a donor so quickly or maybe even at all.

So, that's when I knew I had to get involved with NMDP, or Be The Match as well.

**Elissa:** Yeah, and just to clarify for our listeners, so Be The Match is now called NMDP.

**Dianne:** Yes.

**Elissa:** And so, they've changed their name; and we'll have information in the show notes if people want to look into being donors a little bit later.

**Dianne:** Thank you.

**Holly:** Yeah, so you finally found a donor outside of your family; and can you tell us a little bit about the transplant process itself?

**Dianne:** Absolutely. I will tell you that the leadup and preparation for an autologous transplant using your own cells is harder, in many ways, than the leadup to an unrelated donor transplant. But the recovery from the unrelated donor transplant is a lot harder than the recovery from an autologous transplant. So, we did lots of chemo because the whole idea is to clear out any little cancer cells that may be deciding to hide up in there. So that when you get your new immune system through those stem cells, that it will be able to flourish. So, there's a lot of chemo, a lot of testing in the leadup.

Funny story. So, I could have had my transplant in December of that year, but since the last couple of Decembers had been so rough with me being so sick, I asked my oncologist. "Can we do it in January? Could I just have a Christmas? Because part of it too is, between 30 and 35% of unrelated donors stem cell patients don't survive this transplant. And, of course, having worked with LLS, I knew way too much. I had the statistics. I knew people who didn't survive their transplants. So, I was scared. I mean I was really scared; and so, I thought, well, I better make this a good Christmas if it's maybe going to be my last one.

The funny thing is we usually draw names with my family, and then we have this big Christmas celebration. We knew I couldn't go to that because that was too much exposure to potentially sick people. So, we said, "Well the people whose names we drew come by our house in the late morning, and we'll give you your presents." And then the people who had our names said, "Well, can we come by too because we have presents for you?" And so, we're like, "Yeah."

And so, my husband has this whole station at the front door, gloves and hand sanitizers, mask. I mean he's like, "No entry unless you're completely healthy. And if you feel even a little bit weird, cover, right?" So, everybody said they were healthy, and so we were hanging out for a little while, and I was getting exhausted, and all of a sudden, my sister goes to the bathroom, and she has, at that point, I think 2-year-old granddaughter named Sophia, who wasn't there, but she had just been hanging out with her.

So, my sister Cathy comes out of the bathroom. She's like, "Oh, no. I feel terrible." She was in there throwing up. And we're like, "What?" And so, my son and my husband go into the kitchen. They get the ham, they get the rolls, they get the potatoes, and they just shoving it at people. They're like, "Take the ham and get out. I don't care where you go, but you have to get out of this house." And, then my son takes me into my bedroom. He said, "Do not come out until we say you can come out." So, he Lysol®'d the whole house, and he's like, "Okay, it's safe to come out." By then, it's like 8:00 at night. I'm like, "I'm just going to go to bed."

So, we call that the year of typhoid Sophia because pretty much everybody else in the family got sick. It was a rough Christmas for everyone.

**Elissa:** Oh, goodness.

**Holly:** So, you've now gone through deciding on the transplant. You get through the holidays. You have the transplant, and we know that often patients will develop some form of graft-versus-host disease, or GVHD. Did you have any side effects from the transplant?

**Dianne:** Oh, heck, yes. So, I had acute GVHD in the hospital, to where it was really having, having a heyday in my gastrointestinal tract and my mouth. I had the mouth sores, the throat sores, the, sickness. And so, they had to actually put me on morphine just to handle the pain of the GVHD happening.

And so, it was acute. And then when I went home, we had our 100 days; and I was still having lots of trouble with graft versus host.

And then, what happened was I knew I needed to get back to work for LLS because some changes had been made in our chapter, and they needed the continuity of having a leader. At that point, I was the Area Director, and it felt like I needed to get back. And so, I went back to work a little bit before my oncologist thought was a good idea because I don't always listen, right? So I went back to work in September for Light The Night, and by February graft versus host was attacking me in every system that it does – skin, eyes, lungs, connective tissue, fascia, gastrointestinal tract. I mean everywhere.

And so, I went to see my oncologist, and he said, "Well, you're done." And I'm like, "What are you talking about?" And he said, "I can't keep you alive if you keep working like this." And that's when I found out that GVHD is potentially fatal. I mean people die from this, and I should have known that, but I didn't. And he's like, "You have to go on long-term disability, and we have to get this managed, and we're going to have to keep managing this probably for the rest of your life."

So, I was 48 at the time. I was at the top of my game. I was having this huge impact for our organization, and I had to stop because I absolutely did want to live. I mean you don't go through all that and just be like, "Oh, well, whatever." So, graft versus host has been my constant companion ever since.

**Elissa:** Wow. So, let's step back and talk about a little bit happier things.

**Dianne:** Yeah.

**Elissa:** So, one thing you've talked a little bit about your involvement in Light The Night. I do want to hear, because you shared with me prior to the podcast that it was a little bit connected to your wedding. Could you tell us about that?

**Dianne:** Yes. So my background is media and PR and communications. I've mostly worked with nonprofits and school systems. So, when I got in remission in early 2008, Chuck and I thought we want to do something with LLS because if it wasn't for LLS, I would not have survived, right?

So, I get on the computer, and I see Team in Training. I'm like, "Wow, look at this. Team in Training. Maybe we could do this." And so, I have to tell you, I met Chuck on Match.com®. We lived a mile apart, but we met on the computer. And when I talked about Team in Training, he said. "Dianne, remember my profile where I said if you're looking for someone to go rock climbing with, I'm not your guy. Go hiking." He's like, "That still applies." And so-

**Elissa:** I will not be your partner in this.

**Dianne:** No. He's like, "I'm not doing a marathon. What are you-? What?" And so, he's like, "Do they have anything else? Anything else we can do? Just not that. I was like, okay, so I get back on there, and I find Light The Night. And I say, "Hey, they have a walk, and it's like only two miles. I mean, we walk more than that at Disneyland®. I think we can do this. And he's like, "Yeah, let's do that."

So, I signed up right away, and the very next day I get a call from a staff member, and we sit down and meet and talk about this team idea. And so, we're having lunch, and she says, "You know, I think that your team could raise $10,000." And I said, "What are you talking about?" And I'm like, "I thought maybe $2,000." And she's like, "No, you have this great story." So, I was like, "Okay, well, all we can do is try."

So, we decided that we would shoot for that. And then I get a call saying, "Could we share your story? Would you allow us to send a press release out to the media to see if they're, interested in, your story" because, of course, we were planning our wedding at the same time. And so, I said, "Sure." And then they said, "Do you want to get married at the walk?" And at that point I was like, "Yeah, no. Okay, I think we've gone a little too far. I don't think I want to have my wedding in the parking lot of Angel Stadium." So, I said, "Here's what we can do." I said, "Let's combine the wedding and the walk." So, we got married in our backyard on Friday night, and then I got a bus donated; and the next day we took everybody down to Angels Stadium, so we get to be "Team I Do".

**Elissa:** Awe!

**Dianne:** And we came up with that name because we felt like it applies to all of us because who wants to cure cancer? I do. So they decorated our tent; and we raised about $12,000. It was really special to combine the start of the next part of my life with getting involved with LLS because, again, I wouldn't have survived long enough to get married if it wasn't for LLS.

**Holly:** Well, that's a pretty epic way to attend your very first Light The Night. I'm very curious what your involvement has been with Light The Night since then.

**Dianne:** Well, as I said, I got the call to come and run the Light The Night program, and I said, "Yes." Crazy. So, I jumped in, and I was helping get candidates for what was then Man and Woman of the Year at the same time as trying to learn how to run the Light The Night program.

But I loved it. I met so many wonderful people, and at that time my little team, two others and I were running the Inland Empire Walk and the Orange County Walk in Southern California; and we built those walks to $1.5 million in revenue. So, I was really proud of that.

**Elissa:** Wow.

**Dianne:** I've stayed involved with LLS even when I had to stop working. So, now I still do Light The Night. I also ran for Woman of the Year in 2017.

**Elissa:** Wonderful.

**Dianne:** We raised a lot of money, but I didn't win, which I was so excited about because that meant somebody raised a whole lot more money for the mission.

**Elissa:** How much did you raise?

**Dianne:** We raised about $75,000, which was a lot, you know, in 2017. And, okay, so one of the things that I started to do as a fundraiser in 2008 when we were first in Light The Night, I was like, "Okay, they want us to raise $10,000. What the heck am I going to do? How do I even do that, right, because that's going to be more than just asking people to make a donation?"

So, I created an event called The Survivor Strut Fashion Show. And it's called the Survivor Strut because all of the models are cancer survivors. And so that year we had

12 women who modeled, and we raised about $3,500, which I thought was really, really good, right?

**Elissa:** Yeah.

**Dianne:** And then when I started working for LLS, I couldn't do that event for my team when I was trying to lead all these other teams. So, one of my corporate teams did the Survivor Strut for two years, and they were raising more and more money. And then, after I stopped working for LLS, I started doing the Survivor Strut again. And it's not annually. It's every couple years, maybe every three years. In 2017, I had it all planned to do the Survivor Strut, but I got so sick, I ended up in the hospital; so we had to cancel it. So, we still raised $75,000 without even doing the main event.

**Elissa:** Yeah.

**Dianne:** So, in 2021, I decided to run for Woman of the Year All Star, the All-Star campaign. When you've done it once, now you're like, "I could do it so much better." But it was COVID, so we had to do the fashion show as a virtual event. We had the models go to this really cool classic car museum; and we videotaped them strutting their stuff and standing next to these amazing cars, right? And then we cut it all together, and we had an online event, an online fashion show. And we raised about $150,000 that year, and I was named National Woman of the Year All Star for LLS.

**Elissa:** Yay, so you finally won.

**Holly:** Amazing.

**Dianne:** I was super proud of that because it's hard to raise money in the middle of a pandemic.

**Elissa:** Yeah.

**Dianne:** It's not an easy time of life.

**Elissa:** Yeah, and that is the time I feel like when we needed it the most.

**Dianne:** Yes.

**Elissa:** You know, everybody was locked down; and we still needed to get research funded. It was so many important things.

**Dianne:** Yes. We had commitments to these scientists and researchers, and it's like we can't not do it, and we can't not raise the money. I was desperate. I did practically anything to raise money that year.

**Elissa:** That's wonderful. And before we move on, I want to make a couple of clarifications to our listeners about these two events. So, Light The Night, the walking is optional. So, if you are not mobile, please still come because the ceremony is the highlight of the event. And that is so important and beautiful, and so please look for your local Light The Night and try to attend, particularly, if you are a patient or survivor listening. It's a beautiful event. And then for Man and Woman of the Year, it is now called Visionaries of the Year. And so, it's still going, still this amazing, incredible event, and so that's amazing that you won the National Woman of the Year.

And so, moving on a bit, now you and I first met at the LLS Spring Lobby Day in DC this year, where we were meeting with our state representatives and senators to fight against the healthcare cuts-

**Dianne:** Yes.

**Elissa:** -for cancer patients. And so, could you tell us how you got involved with legislative patient advocacy?

**Dianne:** So, I first got involved with advocacy as a volunteer with NMDP, formerly Be The Match. And, they have a great program. And because here's the situation. If you think about all of the people that have gone through blood cancer, imagine that's a giant lake. It's like Lake Michigan. But the people within that population who have also then gone through unrelated donor stem cell transplant is a small island in the middle of that giant lake. And I thought I'm fully vested and involved with LLS. But because I have this additional experience, and again because I wouldn't be here if there were no Be The Match registry, there were no NMDP organization, I felt like I needed to get involved with them as well because I swim in the lake, and I stand on the island, right? So, I got involved with them and started doing some advocacy, but I have to admit I wasn't the best at it at that point.

But then, I think it was later last year my Executive Director for LLS contacted me and said, "We need you to get into advocacy for us because we need to talk to the representatives and senators where you're a constituent. Would you consider joining us in this effort?" And I said, "Yes." I say yes a lot. So, I said yes and flew out to DC where we met in person; and the training was so phenomenal to understand how the process works, to understand how our voice has so much weight and can make a huge difference. And something happened there, and I said, "So, I now have survived for 18 years since my first diagnosis, meaning I basically just graduated cancer high school, right?" And I thought I've helped lead raising millions. I've raised almost a quarter of a million, me and my family, ourselves. But, if patients don't have access to healthcare and to these treatments, what's it all for?

**Elissa:** Yeah, what's the point in doing all this research-

**Dianne:** Exactly.

**Elissa:** -if they can't access the treatments?

**Dianne:** So, then I thought, okay, so now I've graduated high school, it's time for me to go to some grad school and get involved with advocacy and let my voice stand for hundreds of thousands of people and try to, influence our legislators to care enough to be brave and stand against the kinds of cuts that were part of that budget resolution bill.

And at this point, we all know that that bill did pass. But that doesn't stop the work. We have to keep talking to these legislators. We have to keep telling them about the impact. They talk a lot about the group that has the most financial challenges, the most needy people. And I'm like what you don't understand, it's your thinking this is like these people who are barely making it, even people who are firmly in the middle class, one diagnosis puts you into the most needy group.

**Elissa:** Yeah, that can bankrupt people.

**Dianne:** It bankrupted us. We filed for bankruptcy and I had great insurance. But imagine what happens. I had to stop working and go on disability if I wanted to live. So, I cut my income by half; and there's no money being paid into my 401(k) to secure my financial future. And it costs a lot of money, even when you have good insurance for all your medications and things. And so yeah, we did file for bankruptcy; and we're the lucky ones.

**Elissa:** Yeah. One thing that stuck with me when we were at the Lobby Day, which is I feel like, makes it very important for patients to get involved, patients and caregivers-

**Dianne:** Yes.

**Elissa:** -to share their story. It's sharing your story was getting you off of the spreadsheet of just being a number, right?

**Dianne:** Yes.

**Elissa:** You're, no longer a number. You're a human being with a story. You've shared your struggles. You've shared what you went through. I shared my story of being on Medicaid and that paying my healthcare premium so that I could just be able to survive.

**Dianne:** Right.

**Elissa:** And, it was so important to be able to share your own story. So, again, you are not just a number on a page. We matter, and our stories matter, and it makes, that issue so much more human.

**Dianne:** Absolutely. It puts the faith, it puts the experience right in front of the, teams that, set our laws. But, there's another part of it that is important to talk about, which is it can be part of your healing to do this kind of work, to tell your story, to tell your child's story, whomever it is. It is a way to find meaning and purpose from the hard things that you've gone through. And that could be any hard thing, really.

But I encourage people to consider being a legislative advocate because it's the fundamental foundation of our country and our democracy to be heard. It was an amazing day; and I am still so proud of the team that I was working with, with the meetings that we had and all the stories that were told. And we've, really reached these staff members and legislators; and we can't stop. Those stories need to keep being told, and so we always need new people to share their new stories.

**Elissa:** Yes, and we'll have, a link in the show notes of how to get involved. And it can be as simple as punching a number in your phone, and they'll have letters written for you that you can just add to or you can actually get involved on a deeper level-

**Dianne:** Yes.

**Elissa:** -like Dianne did.

**Holly:** And healing, of course. That word in itself is so powerful, right?

**Dianne:** Yes.

**Holly:** Which segues me into our next topic, which often can be put on the backburner, the emotional toll of cancer. So, Dianne, I want to know what was that like for you having dealt with cancer multiple times over the years?

**Dianne:** You know, I took a deep breath because that is a deep and important part of managing this journey, this journey through illness which is the name of my next book. And I write about that a lot because, oftentimes, we feel like we have to put on such a strong face and sometimes we're in a situation where our families, our caregivers, our loved ones, they need that. They're having trouble handling their own emotions, right?

What I've learned is there's no way to avoid the deepest, truest emotions. There is grief even in survival because a health journey, a health fight, a diagnosis, that is a loss as well as a struggle because sometimes you lose your autonomy. I mean, three years ago when I was diagnosed with breast cancer, I had to have a double mastectomy; and I'm not a candidate for reconstruction because I have graft versus host, I'm immune suppressed, my lungs have been damaged. My surgeon literally said, "I don't know a plastic surgeon who would touch you with a ten-foot pole. It is too dangerous for you. And she said, "You know, we have so many support groups. A lot of women feel like they're no longer womanly or feminine" and I said, "You know what, I'm so glad you have those groups, but I'm not going to need them" because I had been doing all this work, even before I got diagnosed with cancer 18 years ago, on reclaiming my confidence and reclaiming my sense of worth as a human being. But I knew I was going to be fine. I was going to be great.

So, all that to say that you do go through loss, you do go through grief. You may feel like you lose your looks. You may feel like you may lose some of your physical capacity. I volunteer with NMDP, like I said, and I help facilitate survivorship calls. And we have people that say, "I was very athletic. I ran marathons," and I'm like, "Well, that wasn't me." But now I cannot do it, and they struggle with the grief and the loss that cancer can mean in your life.

So I've struggled with the same things. I have also tried my best to remain optimistic, to continue to believe that there is beauty and there are wonderful things in life, even on the days where I'm on my fifth week in the hospital with my transplant; and all I can still do is sleep or cry or vomit. Because what I've learned through all the reading is that a positive outlook, and that doesn't mean you pretend that this isn't hard. But if you try to look for something joyful in each day, it is a kind of magical medicine that helps you. It helps you withstand your treatment better. I'm a speaker. I go across the country and I speak about these things. And I'm like, "This is the work that you can take on right now is to work on looking for the joyful things," even in the middle of the biggest storm.

**Elissa:** Yeah. Now let's talk about your books because you did mention that you write this in your books. So, you've now written four, one of which is coming out very soon.

**Dianne:** Yes.

**Elissa:** Could you tell us a little bit more about these books and what they're about and why it was important for you to write these.

**Dianne:** Well, my very first book I wrote in 2018, and it's called, "Lighthearted Life: Simple Strategies to Live a Joy-Filled Life, Even in the Stormiest Times." So, basically, what I was just saying, right?

At that point, I had been on disability for a while; and I had to really think about what is my new purpose. I was really clear about my prior purpose, raise as much money as possible, keep those researchers in their labs so that they can find breakthrough treatments like CAR T-cell therapy and things like that that will save lives.

Then when I'm on my own, I'm like, "Now what do I do?" I mean I can't work full time. I have to take naps. I have, all this medication, but I still have things I can do. And, really the message I got was I'm here to encourage people. So that's where that book came from. It came from researching scientific ways to bring more joy into your life, to be happier, to embrace gratitude, and those were all the things I was speaking about on stages across the country. So, that's where that book came from.

I had started working on my next book right after that, and it's been a long journey. So, the book that's coming out in September is called, *Journey Through Illness: The Ultimate Guidebook for a Trip You Never Thought You'd Take.* And it will launch on September 10, and it was very important to me to launch it in September because it's *Blood Cancer Awareness Month*.

**Elissa:** Yes.

**Dianne:** And I'm going to be donating a portion of the proceeds of sales during September, October, and November, during Light The Night season to LLS.

**<u>Holly</u>:** That's wonderful.

**<u>Elissa</u>:** Very nice.

**<u>Dianne</u>:** That book, it's funny how timing works because I swear, I thought I was going to get it done in like 2020, right? And then for many different reasons, it just wasn't happening. And then three years ago I got the breast cancer, and I was like, "Oh, so now I have a whole 'nother experience of this journey through illness," and so that helped make the book deeper.

And so, I share some of my story sort of anecdotally. It's not like, "Hi, here's Dianne Callahan's story of cancer." There's a lot of books like that, that are really wonderful. I wanted to actually write a guidebook, like, what do you pack for a journey like this? Will you pack your hope and your faith and you pack your friendships, and you pack your sense of humor. I mean, you've got to be ready to laugh because there is always-

I'll tell you a funny story. After my first transplant, I was recovering, and I get a call from a national magazine; and the young lady said, "Oh, Mrs. Callahan, we noticed that your subscription has lapsed; and we'd love to have you come back. We have a two-year subscription. Buy one year, get one free, and so can I just go ahead and get you signed up?" And I said, "Well, I let that lapse because I'm trying to simplify my life because I'm in the middle of some pretty serious cancer treatment." And she goes, "Oh, well, we have six-month subscriptions."

**<u>Elissa</u>:** Oh, no.

**<u>Dianne</u>:** And I almost died laughing. I was like, "I'm not sure if you're a marketing genius or if you just don't understand how that would feel. You might die, so just get six months." But you have to laugh, and so I write about things like that. I write about what the journey of the caregiver is like because we don't talk about that journey very often. There are not a lot of books about that or movies or anything where the caregivers can learn how to do this because the patient doesn't have a choice. The caregivers do. And I wrote a job description. I'm like, "Who would want this job? Nobody."

And I write about who you might meet on the journey, fellow travelers, fellow cancer patients or people in the chemo waiting room. And I write about the souvenirs because if you go on a journey, you want to bring back some souvenirs, right? So, you might bring back a renewed purpose or a different kind of gratitude, things like that.

And then I wrap it up by writing about how there's no back to normal.  We want it so desperately, right, with that gentlemen I mentioned that was a marathon runner.  He was holding on so tight to that version of him that he couldn't enjoy his life in his current version.

And what I've learned is there's never back to quote "normal."  You only go forward.  So, if we're going forward, let's go forward to better.  Let's find a way to let go of what we're holding onto so tightly.  And then I wrap it up by talking about my motto, which is live urgently.  Say the things that need to be said now.  Make sure people that you love and care about know it now.  Take care of your business now.  And go to the beach.  Eat the cheesecake.  Buy the shoes.  Live it up.  And I'm not saying like, spend every last penny because you might die.  We're all going to die.  Let's get used to that, and let's live a life that brings joy to us and others.

**Holly:**  Definitely, let's live a life that brings joy.

**Dianne:**  Yes.

**Holly:**  And that brings me to our next topic.

**Dianne:**  Yes.

**Holly:**  And you mentioned it earlier, Dianne, was bringing bits of joyfulness into your day.  And that is so important.  So, do you have a couple of strategies to bring joy in that you could share with our listeners today?

**Dianne:**  Absolutely.  I think that the important thing is to be intentional, right?  To not be just a passenger in your life's journey.  So, you decide, you choose that you are going to have joy in your life and not just have joy, but recognize the fact that you have it and, and, and savor it.

So, I love to ask people to write their joy list, like the little sparks.  I had a friend when I worked in the Bay Area, actually, and she said her joy sign was seeing a white limousine.  That was a sign that just perked her up, because you see a lot of black ones, right?  But white ones.  And so, when I lived there, I thought, okay, all right, I love Disneyland; but I was living far away.  So, my joy sign was to see a Disney bumper sticker in the Bay Area.  And that's been a joy sign for me for a long time.

But also, you look for things that are life, right?  And you understand that two things can be true or more than two at the same time.  You could be puking your guts out in the middle of a stem cell transplant, and flowers can be blooming at the same time.  So, do you just focus on how bad you feel, or do you look out the window and say, "Well, you know, that daffodil is awesome.  That's beautiful.  Life continues.  Let me find ways to tap into that."

And everybody's ways are different.  I always suggest to have a playlist of the songs that make you, , happy or make you dance.  And my signature song is *Walking on Sunshine*. That's my song.

**Elissa:**  Love it.

**Dianne:**  And that's a good song whenever it comes on, right?  Yeah, so things like that.

And another thing I would say is to remember when you are on a journey through illness, any kind of struggle, there is healing in helping other people.  You get healed when you help other people through their own struggle; and so that's a sense of joy too because what, we want is we want to feel like our lives have mattered, right?  At the end of our life, we're going to wonder did I love as well as I can?  Did I receive love?  Did I matter?  And you don't want to get there and think, I blew it.  So, live urgently now, and give purpose to these hard things.  Give meaning.

**Elissa:**  That is beautiful advice.  Now, our final question today, Dianne, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope."  What would you say to patients and their loved ones to give them hope after a diagnosis of cancer?

**Dianne:**  The first thing I would suggest is talk to your doctors, not Dr. Google, right?

**Elissa:**  Yes, very important.

**Dianne:**  Very important because there's information out there that may not be as up to date as what your doctor has and may not actually match your situation – your age, your health, things like that.  So, try really hard to avoid doomsday stuff, because that doesn't have to apply to you.

And even, any of those mortality statistics, why wouldn't you be in the good group, so to speak?  I don't want to say you have to, but it's good to intentionally seek the hopeful side. Seek the joyful side because, things happen in our lives when we are faced with the end of our lives. When you get a diagnosis of a life-threatening illness, when you get a diagnosis of cancer and there's X percent survive five years or more, X percent don't, those are all numbers, right?

But it's actually a gift too because most of us don't take time, make time, have time to face some of those big questions in our life, to fix some of the things in our lives that would be sad if they're never fixed and we didn't get a chance to. So, this is a gift in many ways, and so I say take it. Take the gift and let it change you in the way it's meant to change you. If anybody does yoga, all the instructors are always saying, "Soften into the pose. Take that breath and let your body soften into the pose." And I've really applied that to my cancer journey. You have to soften into the cancer journey. Soften into acceptance so that it can help you grow and change in the way it's meant to. Because if hard things don't happen in our lives, we won't grow, we won't learn how to accept help, we won't learn how to be givers of help, right?

**Elissa:** Right.

**Dianne:** We'll just go along thinking it's hunky dory. So, accept the gift is part of the hope.

**Elissa:** I love that. Well, thank you so much, Dianne, for joining us today. I loved hearing about your story and your wedding. That was so cute. So, we really appreciate you telling all the things that are so important to, cancer patients, whether it is, talking about the emotional toll or getting involved in patient advocacy and fundraising. And so, again, we really appreciate you joining us today.

**Dianne:** It's been a pleasure, and I am so looking forward to this Light The Night season. I hope to see you guys out there. I'll have a booth at seven or eight different walks, so I can't wait to meet even more people.

**Elissa:** Absolutely. We'll see you there.

**Dianne:** Okay.

**Holly:** Thanks, Dianne.

**<u>Elissa</u>:** 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.

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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.

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