

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Live Your Life: Navigating Mental Health and Chronic Lymphocytic Leukemia (CLL)

Description:

Join us on a heartfelt journey woven by support and education, as we speak to Teresa Altemeyer, who was diagnosed with chronic lymphocytic leukemia in 2009. In this episode, Teresa shares her experience with CLL from diagnosis through long-term survivorship. On the advice of her doctor, she went out to live her life, and found herself supporting other blood cancer patients and survivors in doing the same. Despite her own physical and mental health struggles with this disease, she shares beautiful advice learned along the way.

Transcript:

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

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

Elissa: Today, we will be speaking to Teresa Altemeyer who was diagnosed with chronic lymphocytic leukemia, or CLL, in June of 2009. After five years of watch and wait, she entered a clinical trial for a new medication and was in remission from 2018 through 2023 when she started a new combination therapy.

Shortly after her diagnosis, she was asked by her oncologist to co-facilitate a new blood cancer support group. This support group has now been ongoing since January of 2010. During her time as a co-facilitator, she has seen firsthand how blood cancer patients have emotionally struggled throughout their diagnosis and treatment. This encouraged her to get more involved with LLS to get better educated about blood

cancers and also volunteer with patient outreach, fundraise for Light the Night, advocate with LLS on Capitol Hill, and join her local region LLS Board of Directors.

Welcome, Teresa.

Teresa Altemeyer: Thank you, Elissa. It's nice to be here.

Elissa: So, our episode today is on mental health while living with chronic lymphocytic leukemia, or CLL. Let's start with your diagnosis of CLL. How did you end up being diagnosed in 2009? Did you have any symptoms that initially brought you to the doctor?

Teresa: I did not have any symptoms that brought me to the doctor. I just had an ache in my right shoulder, and I went in to see an orthopedic surgeon. And they did an MRI of my right shoulder, and about two-thirds of the way through, the technician got up and left the room. A few minutes later the orthopedic surgeon came in, and he was crying. He said, "When I went into this profession, I did it because I did not ever want to have to tell somebody what I have to tell you. I can tell that you have lymphoma. You need to go out and find a doctor to help you."

Elissa: Oh, my gosh.

Lizette: Wow.

Teresa: And then the first lesson and piece of advice that I could share with anybody is to do something like what I did. I called my neighbor who lives right across the street because she is a nurse at the cancer center, and I knew she would be able to tell me what to do. I was using information from sources that were around me.

She asked me to get her all of the results that had come from the MRI. I got them to her within an hour or two. She called me back one hour after I handed them to her, and she had arranged for a biopsy to take place, and she had arranged for me, a week out, to have the first doctor appointments.

Elissa: Wow.

Teresa: The diagnosis was confirmed as CLL. In the first appointment, the two doctors that I met with – one was a veteran lymphoma specialist who actually trains all the fellows at the local cancer center, and the second person was a young doctor who had just finished his fellowship, and it was his very first day that he was eligible to see patients. I was actually his first patient.

Elissa: Oh.

Teresa: He was the only Indiana CLL doctor. The conversation went as you might expect it to have gone. There were discussions about the disease, about what expectations could be; but I had a couple of important questions I wanted to ask. I wanted to know how they would feel if I sought a second opinion. They both smiled, looked at me and said, "That's a wonderful idea." So, right, away, I knew I was in a good place.

Elissa: Yes.

Teresa: They said living where we live, there are a lot of choices that could be made. I'm in Indianapolis, and I could go to Chicago. I could go to Louisville, but they said, "There's a Dr. John Byrd who is at Ohio State University in Columbus, Ohio. Why not just go two hours and 45 minutes down the road?" And then he said the most important thing of the day. They said, "What you must do is go out and live your life," and that's what I've done all these years.

Lizette: And so, did you go down the road and see Dr. Byrd?

Teresa: I did go down the road and see Dr. Byrd, and that ties in a little bit to what eventually happened with my treatments.

I waited until about October before I went to see him, and he did some very, very comprehensive testing and determined that I had poor genetics. I have what's called



a complex karyotype, which means I had more than three genetic anomalies and projected that I would be about one to three years before I'd need treatment.

It turned out to be five years in which I was a wait and watch. Those would be the years between 2009 and 2014. But what was ironic was that this would parallel the five years in which astonishing treatment breakthroughs were being made for diseases like CLL. It was timing it perfectly.

We have a saying in our family. Luck, timing, and talent; and luck and timing were on my side. I was absolutely committed to avoiding chemotherapy if there was any way possible. FR (fludarabine and rituximab) and FCR (Fludarabine-cyclophosphamide-rituximab) were the chemo choices at the time, but I knew that relapsed and refractory patients, who had a former treatment, had access to something new on the market called BTK blockers or ibrutinib; but there was no access for me because I was chemo-naïve. I hadn't had any treatments.

But through Dr. Byrd, I became the 30th person in the world to go on a second-generation blocker. The name of this blocker eventually would be acalabrutinib. When I would go to Ohio State University and walk in, everybody called this the "Happy Trial" because everyone who was on it was doing so well. I would be on acalabrutinib for four years because the thought process was that you go on these blockers indefinitely.

But I had a small heart anomaly, and they weren't sure whether or not the cause was the acalabrutinib or not. So, as a precaution, they took me off of it. It turns out, it wasn't the acalabrutinib. But I got almost four more years after that of being in remission for a total of eight years.

Then, in April of 2023, one year ago, the nodes were growing again. This time there was a different recommendation. Both my local doctors, as well as Dr. Byrd, agreed that I should use obinutuzumab and venetoclax. Obinutuzumab is a chemotherapy that's administered in six different infusions, six different times. And venetoclax is a pill that you take. It's a different kind of blocker, a BCL blocker. But what was really

very personally pleasing for myself was the fact that during the time that I had been involved with LLS, which had been almost seven years, I felt like we were raising money for venetoclax. I'd followed that drug. I knew that we'd funded it to almost \$30 million. This doctor who was working on it in Melbourne, Australia, and I had a feeling it had a special place in my life.

So, I've been on venetoclax for one year now, and they will test to see what measurable [residual] disease (MRD) I have left and see whether or not I'll be able to go off, potentially, in two or three weeks.

Elissa: That's wonderful.

Lizette: So, initially you were on watch and wait or active monitoring for a while; and then you started medication through the clinical trial, right?

Teresa: Correct.

Lizette: Okay. So how did you know about clinical trials or that clinical trial? Was it a discussion between you and your doctors?

Teresa: When you go to Ohio State University and are there as a patient for the first time, you have a meeting about clinical trials. And again, I said luck, timing, and talent. The timing was right. If my only option at that point in time to avoid chemotherapy was this second-generation drug, we all knew how effective ibrutinib had been, there was every reason to believe that this would be a very successful drug also.

I had studied, read about it, and knew that it was developed by the same gentleman who developed ibrutinib. So, yes, I also am of a personality that I've always been interested in clinical trials because of the great benefit they have both for potentially the patient as well as for other patients. It really makes a difference.

Elissa: It really does. We talk about shared decision-making quite a bit, particularly with CLL patients, since you may go through several treatments or watch and wait; and so it sounds like you really went into that with your doctor to look at all the different treatments available, to look at clinical trials and really make that decision with your doctor at how you were going to proceed with this, right?

Teresa: Yes. I refused to make decisions without having both my national doctor, Dr. Byrd, and my local doctor in concurrence. And when this was proposed to me, I came back; and my local doctor spent two hours with me reviewing all the pros and cons. It was medicine at its finest.

Elissa: And you talked about, all the research that had come up, from that time since you were diagnosed to the time when you had started that clinical trial; and you're right that, I feel like that 2017 year seemed to be that breakthrough year for so many blood cancers to where we were just seeing all these new treatments come out, all these new clinical trials starting that have now, developed approved medications, which is just so exciting. So, that's wonderful that you were able to come right in at that time, right when a new drug was in trials that seemed to do very well for you.

Teresa: Yeah. You brought up a point just a moment ago about shared decision-making. One of the tenets that I believe in that can help a patient more than anything else is to build your knowledge foundation specifically about your disease and about what I call survival knowledge.

And the reason you want to build your knowledge about the disease is because often when you're in with a doctor and you ask a question, the answer that you really want to get to is not in the first question. It may not be in the second, and it may not be in the third question. But if you don't have a platform for your cancer questions, you may never be able to effectively advocate and truly be part of the decision-making.

In today's, newer treatment paradigm, there's sometimes multiple choices that you can make about what treatment's best for you; and knowledge helps to be able to make



the right decision for yourself. Increasingly, these treatments are just really not one size fits all.

And I think I'm probably a good example of that because, when my cancer developed and was active, I was ready. I knew what was going on. I knew about what new drugs were out there, even though they may or may not have been available. I'd been studying it at a real high level, and my knowledge foundation was in place. So, through conversations with my doctor and my own pursuit of information, I determined that this was the right thing to do.

You've got to build that knowledge foundation. It's just absolutely critical.

Elissa: And we absolutely love to hear that because that is exactly what we're doing with the podcast. That is what we're doing at LLS. We want to educate you on your disease so that you'll hopefully go back to your doctor and make those decisions together and make educated decisions for your treatments. So, that's wonderful to hear that, that is the path that you went down.

Now, a few months after your diagnosis, you were asked to start a support group by your oncologist. Could you tell us how that came about?

Teresa: Yes, I will, Elissa. I was scheduled for appointments every three months. So, now it was October, and I was there for my second appointment. And I walked in with armloads full of flowers. I'm a gardener, and I grow dinnerplate dahlias. And when I say dinnerplate size, that's the size of these flowers. They're massive. They're 12 inches across.

Elissa: Oh.

Lizette: Wow.

Elissa: That's huge.

Teresa: And I plant, 75 plants. So, I had hundreds of dahlias. I give them to people who are meeting a challenge in their life or people who are celebrating something, and I've done this for years.

I had a perfusion of blossoms that year, so I took them into my doctor and his nurse and the staff. And he remembered that, I guess, because on the third visit with him, as it was concluding, he said to me, "I have a favor to ask of you." He had had a patient die, and on their deathbed they had made him promise that he would bring up a group, so that that patient and other patients would never have to live through what they lived through without other people to share and confide and talk about what, they were experiencing in their life. And my doctor was keeping his promise, and he asked me if I would be the facilitator for the patients; and I said, "Yes, I would." I guess you might ask why would I say yes so quickly. I knew nothing about facilitating. I knew nothing about support groups. But it just felt right.

I needed to be prepared to deal with what could possibly be confronted in the support group.

So, I started going to conferences with doctors, and trying to learn their language. And, then I found LLS, who today helps fund the support group.

Elissa: Wonderful.

Teresa: I mentioned building a foundation of disease knowledge, but you also have to develop what I call survival knowledge because 99% of the time, you're not with a doctor. They serve as the master lynchpins in your cancer healthcare, of course. But there'll never be enough time during the doctor visit to get all the questions answered or asked that a patient's going to have about their disease, let alone complementary resources.



The reality is that we live in a world where the vast majority of our time is spent away from a doctor's office, and there'll always be questions that we didn't even know we wanted to ask or needed to ask when we were in the doctor's presence.

These are questions that I think come to you deep in the night, leaving one trying to figure out where to turn. And they may range from cancer financial bankruptcy, hospital transportation, the nuances of Medicare, to getting accurate information and deeper understanding so you can be prepared the next time you're with a doctor.

It creates a lot of stress, but there's a lot of solutions for these things. And one of them I feel strongly is a support group. And support groups have all kinds of different structures. The structure that we have is the evening, we meet for an hour and a half once a month. There is a social worker who joins us, and she's sort of the official representative from the hospital because she knows all the services in-depth that are available. About every other month we bring in a specialist or somebody in the area. I mean we've 170 meetings at this point.

Elissa: Wow.

Teresa: There are almost too many specialists for me to identify; but I would want you to file away in your memory bank that there's that kind of support. It's there in many hospitals.

In our group, we discuss a lot about the importance of empathy, how hard it is to envision each other's worlds between a patient, a caregiver, a doctor, a friend, a child, the parent. It's a continuous theme trying to clarify our view into the world of those who are most important to us and their view back into us as cancer patients.

I think a witness to the success of this program is at the end of the meetings the attendees used to stay. It would be 7:30 in the evening, and it's black outside because it's the winter; and they'd want to stay and share and inform. And at one



meeting recently, it concluded with a participant saying, "This is my other family" and another one saying, "This group saved my life."

And so, we have shared difficult times in members' health. We've helped think through, strategize to become more informed in facing inevitable decisions, in coping mentally, in communicating with doctors. That's a big one. In seeking other opinions or looking for clinical trials. We've made hospital visits. We've driven hours taking fellow patients to find places where unique clinical trials were offered, and we've written notes and appointments with doctors so that a second set of ears is there. We do a lot, and we care for each other a great deal.

I think one of the most satisfying moments in a support group is when somebody comes for the first time.

Elissa: Yeah.

Teresa: And those of us who's been there for a while, we sort of glance at each other; and we know what's going to happen. We know what that evening will look like. There will probably be tears, but we also know that when that person leaves the group, they'll probably have a smile on their face.

Lizette: A wonderful support system. Now, you being a patient and helping to facilitate the support group, how has it affected you?

Teresa: It's probably the greatest gift that's ever been given to me. I didn't think of it that way initially, but as time has gone by and almost 15 years is a long time to do this. I found that it made me strong, it educated me. It's educated the whole group. I think if you were to ask anyone in the group, they would say that they've determined that this acquisition of knowledge is the most important thing they can do to help themselves with their disease because knowledge equals control, and control makes you powerful. Powerful enough to deal with the struggles that you inevitably will have.

I sometimes I feel like I'm selfish. It's been so wonderful. And it's so wonderful to look at someone's face when you see that they have reached a solution in their own mind and that they'll be able to live a better life because of what they've heard or experienced. Incredibly satisfying.

Elissa: That's beautiful. Now, what did you see from others in the support group as they dealt with their various blood cancers? Was it different from your own emotions or did you find a lot of commonalities there?

Teresa: I live by that "Go out and live your life," and so when I started with that, everything that I did, I would use to support that or to strengthen that belief and that concept.

Many others were not so fortunate. We all have different personalities. If a thousand of us were diagnosed, you'd get a thousand different reactions. Many of the people who come in and they've been diagnosed with CLL, and they don't have any particular other health issues, they may have a CLL that's been identified as being very neutral, at least genetically. And that they have every reason to maybe be able to believe that they could have a good long, long life. And as they always say, "Never die from your CLL. Die from something else."

But those people, some of them are just absolutely bound and determined, it would seem, to panic, to consider this the most depressing thing that has ever happened in their life, and it may actually be.

They're hearing when they talk to the doctor only the worst prognosis. They're hearing the bad. They're not hearing the good. There's a lot of struggles with trying to balance that out; and I think because there's so many good viewpoints and some very articulate people in this particular group, it goes a long way toward turning people around and improving their mental state and how they define their disease.



You find everything in between from the person who says, "Well, I'm going to go out and lick this cancer, and I'm going to go raise \$100,000 for LLS, and I'm going to make the best of the situation" to someone who can barely get up in the morning and deals with severe mental depression and everything in between.

But I can tell you the support group helps, and I can tell you that even beyond the support group and the doctors and the nurses, there is so much help out there. There are so many resources that can really make a difference for people who are struggling.

We have something at the cancer center, called the Cancer Resource Center, and LLS was one of the five partners that helped to bring this into being. People can use the Resource Center. They can talk to the personnel that are there about how they can resolve whatever issues they're struggling with.

They have music therapy, and I could talk about music therapy for a long time. There was a study done and they found that with music introduced into the lives of patients, the outcomes were better, the hospital stays were shorter, the dispositions were radically improved, and the same thing with art.

There's art therapy at the center because art is linear; and when you have cancer, they talk about chaotic cancer brain. The linearity of the art lets people escape from where they are and find comfort and confidence in something else that's beyond just their cancer. And I really know this personally because I am a professional artist. I'm a professional portrait painter.

Lizette: Wow.

Teresa: And when I go into my studio, I am a world apart; and cancer is the furthest thing from my mind, and it's very healing. And the hospital feels so strongly about this that they have an annual art show. They've done this for six years. And anyone can participate. Anyone who has been involved with cancer and wants to present a vision of what it is in their life. And they prepare their work of art with a statement that goes



with it that tells what they're thinking and where they're coming from. And it's just beautiful.

But back to that Cancer Resource Center. There's massage therapy, yoga therapy, cosmetology. But most of all, I think it helps people to recognize that there are all sorts of people to help them. That there are chaplains, social workers, nurse navigators, psychologists, researchers, specialty pharmacists, specialized clinicians, and, of course, LLS. But all these resources are there, and people just don't often know about it; and it's so important that they learn about these supportive services and take advantage of them because it can be a real difference maker.

Elissa: Absolutely.

Lizette: Yeah, definitely. I think it's great that you're letting everybody know about all of these support services. It's something that most patients don't know when they first become diagnosed. When you're first diagnosed, what are you thinking of?

Teresa: I asked my doctor about this once, and he said, "Teresa, when I'm in the clinic and with a patient, with or without my nurse there, they are telling me what's going on in their medical life. And I'm processing, okay, maybe they need this drug. Maybe it's time to begin treatment. Maybe they need to do this particular thing. They are thinking medical. He said, I am not thinking about supportive services. I am thinking about what I medically do. And he said there has to be a better way, and that's where the Cancer Resource Center came into play.

And many hospitals have these similar services. Many do. They just may be a little harder to find, but most of them are there.

Lizette: Yeah.

Teresa: I feel that you have to choose very carefully your institution. It would be some of the first advice I would give somebody who was diagnosed. There are between 30 and 40 NCI-accredited institutions.



That is where all the best care in the world emanates from. The research that's being done in those facilities is beyond. They see the rare every day, and they see it over and over again.

They all have these specialized services available, but they have a level of specialist that is just beyond what most communities ever get to experience.

I think everyone should get a second opinion. The subtleties between many leukemias and lymphomas are so small that they can be hard to diagnose, even by an expert.

But about getting to these particular institutions, I was able to do that. I wasn't working. I could make that drive. It was something that wasn't extraordinarily impractical.

It can be a real challenge for some people to get there. In that case, I would go for a second opinion; and then I would do a reverse recommendation. I would say in the specialized centers, they know the doctors who are out there in the hinterland, if you will. Get a reverse recommendation for somebody who might be closer in your area who they have faith in and work it backwards.

Elissa: And it's just that same thing as what you're going through. You saw Dr. Byrd, but then he also talked to your local oncologist. And so that is something that rural patients can do is go to see the specialist and then have them, confer with your local doctor to make sure you're getting the best standard of care and access to, new treatment options or clinical trials.

Teresa: Absolutely. These doctors know each other well. They know it by research. They know it by recommendations. They know these names from their patients. They call them regularly, like you just said, for comparative analysis of what's needed. They know their own. They know their peers.



Lizette: Yeah. Now, at some point you decided to start getting involved with LLS through education and then volunteering. Can you tell us about that and how you've gotten involved?

Teresa: Yes, it goes back to when I was on a quest for knowledge. And I began going locally to the various events that were taking place educationally. I went into the office because I understood that there was a lot of literature there that I could get my hands on.

Elissa: Good.

Teresa: LLS has the most wonderful literature in the world in explaining and defining diseases.

And so, eventually the Executive Director of the Indiana Chapter became aware of me because I was sort of hanging around.

And she began extending an invitation for me to go on the Board, and I said, "No, I don't think I can do that. I don't know enough about your institution yet. I'm just not ready. But I'll do some low-level volunteering, and by that I mean, twice a month. I began to go into the office and make phone calls to people who had received the \$100 stipend that LLS makes available to anyone who's diagnosed with a blood cancer. It was a follow-up call, and I would call people and I'd ask if they'd received the funds and if there was anything else we could do for them.

I'd been doing this for about three months, and I was trying to reach a gentleman and instead his wife answered the phone. I asked her if they'd received the funds, and she said, "Yes." And she said, "We are so grateful. We are leaving the hospital right now." This was after being in the hospital for two months with a transplant that had had some problems.

The couple had a small business, and they'd been completely wiped out financially; and the business had to close. And she said, "I'm going home today to sell everything

we own so we can make our insurance payments because without them, we're dead." And I said, "What a minute. Just wait. Let me talk to a few people, and let's see what can be done, if anything. I can't make a promise but let me see."

I gave the information to the staff, and in less than a week they had funds that went a long way with their situation, thousands of dollars. And I walked into the Executive Director's office, and I said, "I'm all in. You've got me. I want to do this."

And, so the question is, why did I volunteer? I think, I felt this vein of destiny running through my life from my doctor who asked me to start a support group to talking with that woman that day on the phone. And once I started, I think one finds a new degree of empathy in life about walking a mile in someone else's shoes; and you end up with a feeling that is so satisfying, you almost feel selfish. You feel like you're getting all this wonderful good from this, from a feeling that you have when you see someone else have a difference made in their lives.

Elissa: Absolutely. Now, you've gone through quite a lot over the past 15 years since your diagnosis with various treatments and then periods of watch and wait. What has been the emotional impact of all of that?

Teresa: Well, we could call those struggles. Well, let's face it, there are times for optimism and there are times when there's not optimism. It's rough because, when you're first diagnosed, there's a feeling of being lost, all alone, and your mind sort of goes blank. And the problem is that for most people, and for me, the world of cancer is a complete unknown. It has its own structure. It has its own rituals. It has its own customs. But most of all, it has its own language; and you don't speak that language.

So, you try your best. This is where knowledge comes in again. But you're in the ultimate test of resilience and making your resilience outlast the cancer. And I'm sure there are many people in the audience who have done that and know what I'm talking about.



I had a few moments of fear, real fear. One of them when I was at a conference in New York. I came home, and I was not hearing good news. It was one of the first conferences I went to. I was not hearing good news about promising drugs on the market at that time. I was staying with my sister in the Bronx (NY); and I cried for hours. I couldn't stop crying. I was so upset; I was so afraid. You become overwhelmed when you're doing fact gathering and trying to make decisions about what you discovered.

And then, you take a deep breath, and you learn that you have to advocate for yourself and that you're going to have to do things with cancer that may not come naturally to your personality. It's easy to overload, but you're on a quest to find out information that will make you strong so that you won't succumb to depression and anxiety.

And you really come to value through cancer, with greater clarity, what is important to you and what you value in life. And you learn you have to fight if you're going to see those graduations, if you're going to see those weddings, and if you're going to see those grandchildren. You have to self-advocate.

I think I chose that path, or maybe because of the support group, was forced into that path; and I'll tell you a little bit more about myself and some of the struggles that I've had. In addition to CLL, I have had a number of other health issues that I've had to deal with; but I've chosen to take what I call the mile-high viewpoint, which I think is good for everything, to try to back away from the immediacy of what you're experiencing and try to have a viewpoint of it in context.

I chose the mile-high view for blood cancer because I was aware of the spectacular treatment options that were going to be out there, so I didn't have to worry about that. There were choices. Lucky me.

In 2018, I was diagnosed with breast cancer, but I knew enough to know that millions have had my same diagnosis, my same version, Stage I, common treatment, no

chemotherapy, just radiation, a low oncotype which helps you determine what the chances are of progression later on, and I knew who the best doctors were. Again, lucky me.

However, five days after the breast cancer diagnosis, I was diagnosed with Parkinson's disease. Parkinson's is tricky. It's not had the success that blood cancers have with treatments, but mine appears to be very slow growing or slow in its occurrence.

And then last year I was diagnosed with a brain tumor, a meningioma. But that's slow growing, it's in a reasonably good location, it was detected early – so again, lucky me.

I had to look at each of these things from the high view because I could see from there how fortunate I was. Each of these diseases could have been devastating, both physically and mentally. It wasn't devastating for me. There were some dark times, and you have to allow that because sometimes you have to have a good cry to cleanse your soul. But in reality, I'm a very fortunate woman.

Lizette: Now, you mentioned struggles. So, what are some of these things that you learned about mental health and the emotional struggles with cancer? And what advice do you have for others, newly diagnosed CLL patients?

Teresa: I think, when a person is in a depressed state, that they have to learn to look outward and not inward. And that is tough. I'm not a professional. But part of that is seeing and being with other people who have a similar circumstance and are able to lift themselves out of it. Seeing that modeled.

Secondly, I'm sure that the social worker who I work with in the support group, would say that you really do need to seek professional help. It's just critically important. People who have suggestions and different approaches for you to take that can really make a difference in your life. And to get over any stigmas that you as a person might associate with mental health or with going to see a counselor because that's often a

showstopper for a lot of people. They view it as a sign of weakness. Well, you've got a battle on your hands, and the experts are the ones who really have a lot of answers.

Someone once defined depression as, "You know you're depressed when you stop loving the things you know you love." And so, we sort of use that as a benchmark to go by.

As you can tell my mantra is that knowledge and self-education goes so far for improving mental disposition and finding those resources that can help you along the way.

Elissa: Absolutely. Now, one final question that we have for today, on our patient podcast home page we have a quote that says, "After diagnosis comes hope." How would you complete that sentence? After diagnosis comes?

Teresa: It's exactly what my doctors said to me. Go out and live your life. Because of the funding that's gone on through entities like LLS for research, there's just so many opportunities that didn't exist previously. I've been talking a great deal about adults. I mean you look at the statistics for children with ALL where 40 years ago, it was a death sentence for a child to be diagnosed. They die in three months. Now what is it, 97, 98% of the kids live and are alive and are leading lives. There's so much help out there to help you build hope.

If you don't mind, I have something I'd like to share. A few years ago, Fred Rogers had been in the media a fair amount because a documentary film was released about his career and his life. And he would be best known to you as Mr. Rogers of PBS fame.

I saw that documentary recently and thought about this podcast because there was a thought toward the end of this film about this kind, gentle man that he shared that stuck in my mind. He was trying to explain to young children how to cope with a major disaster in life. In that case, it was 9/11. In our case, it's cancer.



He said with his soft reassuring voice that in the midst of all this chaos, when disaster is overwhelming you, you must look for the helpers. Always look for the helpers, and you will see them. You will see them everywhere, but you have to look. They'll be saving the situations, they'll be doing good, they'll be righting the wrong, and I found a lot of helpers, particularly at LLS.

Elissa: That's beautiful.

Well, thank you for sharing that; and thank you so much, Teresa, for joining us today on the podcast and sharing all about your own struggles and your diagnosis and then also having some wonderful, beautiful advice for other people. For our listeners, we'll make sure to have links of many different things that Teresa talked about – our mental health resources, the patient aid program she discussed, in our show notes, so be sure to take a look at that. But, again, thank you so much, Teresa, for joining us today.

Teresa: Thank you. It's been a pleasure.

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.

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

In addition to the Lounge, we could use your feedback to help us continue to provide the engaging content for all people affected by cancer. We would like to ask you to complete a brief survey that can be found in the show notes or at TheBloodline.org.



This is your opportunity to provide feedback and suggested topics that will help so many people.

We would also like to know about you and how we can serve you better. The survey is completely anonymous, and no identifying information will be taken. However, if you would like to contact the LLS staff, please email TheBloodline@LLS.org.

We hope this podcast helped you today. Stay tuned for more information on the resources that LLS has for you or your loved ones who have been affected by cancer.

Have you or a loved one been affected by a blood cancer? LLS has many resources available to you – financial support, peer-to-peer connection, nutritional support, and more. We encourage patients and caregivers to contact our Information Specialists at 1-800-955-4572 or go to LLS.org/PatientSupport. You can find more information on chronic lymphocytic leukemia at LLS.org/Leukemia. You can also find mental health resources at LLS.org/MentalHealth. 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.