

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Give Yourself Grace: Overcoming Long-term Side Effects'

Description:

Join us as we speak to Veronika Panagiotou, a non-Hodgkin lymphoma survivor and Alique Topalian, a two-time AML survivor. In this episode, Veronika and Alique discuss the long-term side effects they have been experiencing as a result of their chemotherapy treatments.

While their lives have been impacted by these treatments, they have been able to find joy and peace as they work to overcome these side effects. Don't miss out on this important episode, as blood cancer patients learn to give themselves grace during challenging days in treatment and beyond.

Transcript:

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

Jesse: And 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 Veronika Panagiotou, a non-Hodgkin lymphoma survivor, and Alique Topalian, a two-time acute myeloid leukemia survivor, about long-term effects of chemotherapy. You may recognize their names as they both joined us on the *Bloodline Live* podcast episode from CancerCon that launched in August of 2022.

Veronika was diagnosed with non-Hodgkin lymphoma in 2013, only a few days after celebrating her 25th birthday. Nine years later she continues to use her cancer diagnosis and knowledge she has gained through the process to empower other cancer survivors to tell their stories and support their advocacy.



Veronika currently serves as the Advocacy and Program Manager at the National Coalition for Cancer Survivorship, or NCCS, where she empowers and educates advocates on the most pressing policy issues facing quality cancer care to facilitate their engagement in public policy advocacy.

Alique was diagnosed with acute myeloid leukemia, or AML, in 1998, at age 4, and then again in March of 2021 at age 27. With her diagnosis of AML, she learned that she was the first known person to relapse after 22 years of having no evidence of disease. Following her latest round of treatment, she is now in complete remission.

Growing up a childhood cancer survivor, Alique used her voice to passionately raise awareness about bone marrow and cord blood donation. Her cancer survivorship inspired her to obtain a PhD in Health Promotion and Education, and she now works as a research scientist in survivorship and supportive services at the University of Cincinnati.

Welcome Veronika and Alique.

Alique Topalian: Thank you for having us.

Veronika Panagiotou: Yeah, it's a pleasure.

Elissa: So, Veronika, let's start with you. Tell us about your diagnosis of non-Hodgkin lymphoma. Now there are many types of this lymphoma. What did you have?

Veronika: I had the diffused [large] B cell lymphoma (DLBCL). I was diagnosed a couple days after my 25th birthday. I was a master's student, working with children, at a children's museum, as well as studying to be a child life specialist at the time.

Elissa: Oh!

Veronika: I spent years volunteering at the oncology unit at our local children's hospital.

As I was pushing through in the last semester of the program, I started to feel uneasy. I was losing weight. I started to have a fever that I just couldn't shake. And I'll never forget, one of my colleagues said to me, "Wow, you're losing a lot of weight. You look really good." And I turned to her, and I said, "But I just feel so horrible." And I think that was the first time I realized that something wasn't quite right.

Eventually, my fevers turned into fevers with nausea and vomiting, and eventually I was diagnosed in the emergency room after visiting doctors, trying to find some explanation. And it was cancer.

Jesse: Veronika, what treatments did you have? Are you still in treatment for cancer at all?

Veronika: I went through six rounds of CHOP-R, which is a combination of chemotherapy, immunotherapy, and prednisone. And I was able to go through the standard treatment, six rounds, and was declared NED, no evidence of disease, shortly after.

But these long years of post-treatment, I have dealt with the long-term side effects of chemotherapy, as well as autoimmune issues.

Though I'm not getting chemotherapy, I'm constantly in the care of my doctors and I'm still trying to find a functioning balance of trying to manage all of my long-term new reoccurring symptoms as well as trying to be in good health. That's such a struggle when you have a cancer diagnosis because everything's a lot more complicated.

Elissa: Yeah. You make an important point, that sometimes, even though the treatment is over, that doesn't mean that it's all done. And I think that is definitely misunderstood, particularly by the noncancer community and those who have not gone through this.

Now, Alique, let's discuss your diagnosis for a bit. You have quite a unique case in that you were a childhood survivor of AML, you finished treatment and reached complete remission.

Alique: Yes.

Elissa: But then you were diagnosed with AML again 22 years later. Can you tell us a little about these two diagnoses so many years apart?

Alique: When I was diagnosed in 1998, I was four years old, and my family really started to notice changes in me. Extreme fatigue. I would go outside and play; I'd maybe be able to play for like ten minutes, come inside and have to fall asleep immediately. I had petechiae, little red dots on the skin. And the thing that always stuck out in my mind; that my mom says is how she knew something was wrong was that the light in my eyes was gone.

And that was something I never really understood until I got older. So, she took me to the doctor. We ran a bunch of different tests. It had taken a while to get the diagnosis because, at first, everybody was saying, "Oh, you're just overreacting." But the day of diagnosis I went into the hospital and started nine months of intensive inpatient therapy.

My first time going through treatment, I was participating in one of the original 7+3 trials for pediatric cancer patients. And 7+3 is actually one of the standards of care for AML across the board now. I think that's really unique that I was able to participate in that trial along with the biomarker study, both in the nineties. That really helped pave the way for cancer care in the future. And I didn't even know it yet.

Fast forward 22 years. I had been feeling very sick. I was fatigued, I had petechiae again, except this time I didn't know what petechiae looked like. I hadn't shown anybody, I thought it was just like a rash on my leg, headaches. I was working an absurd amount. I was working about 80 hours a week, so I just really attributed all of



it to burnout. I had more blood work done. I had gotten pushback from my doctors. They kept saying that they thought I was fine, and I was just burnt out. But at this point I was like, "We really need some follow-up testing. Like I do not feel right." And the next day I had my diagnosis, and within two days I was in the hospital.

I did a round of FLAG-IDA, which is a combination of about four different chemo drugs. Then I did five rounds of high-dose Ara-C, and then I did one round of gemtuzumab, which is an immunotherapy. Honestly, the immunotherapy was probably one of the hardest parts of my treatment. I don't know, maybe it was just my brain thinking that it was going to be easier because it wasn't chemo. The side effects of that were more intense even than almost anything else I had been through.

Both times it was recommended that I get a bone marrow transplant. That's one of the typical courses of action with AML. However, the first time I was diagnosed, we were unable to find a match. We were told that our best chance of finding a match would be within the Armenian community because I'm 100% Armenian, and our unique genetic makeup makes it more likely that you would find a match within that community.

My family and I held drives, internationally, and we were still unable to find a match. Lucky enough, though, so many people did register to try and get matched for me who were Armenian, that we were able to found the Armenian Bone Marrow Donor Registry which is still in operation today and has saved multiple lives of Armenians and non-Armenians alike and brought the first stem cell harvesting center and transplant area to Armenia and that entire region of the caucuses. So really providing cutting edge care.

Fast forward 22 years later, they told me they wanted transplant again. We go through the same process. We go back to the ABMDR [Armenian Bone Marrow Donor Registry]. We think, surely, after 23 years that we're going to be able to find a match. It turns out I'm still just as unique as I was that day when I was four years old, and we

were still unable to find a match. So, I was unable to go through with what they consider curative treatment both times.

That really changed my treatment outcomes, both times I went through treatment. The first time they predicted that I had a 13% chance of survival without transplant, and a 20% chance of survival with transplant in the nineties. So, I was very lucky that 7+3 was having that experimental trial at that time, and I contribute that to my long-term survival.

The second time going through, because we were unable to find a match, the numbers changed due to the biomarkers of my disease. I was actually given a 20% chance of five-year survival with transplant because we couldn't find a transplant that was close enough to my makeup. And a 75% percent chance of five-year survival with chemotherapy and immunotherapy alone.

I ended up going that route and because of that I'm now on a long-term maintenance chemotherapy. I am about a year and a half into being on this maintenance chemo right now. I have anywhere from another year and a half to two to three years left on it. I'm hoping for that year and a half mark though. It would be very nice to get off treatment soon.

When I hit the three-year mark of this, I'll be at 36 rounds of maintenance chemo.

Jesse: Well, thank you so much for that detailed explanation of your treatments, and sorry to hear of your diagnosis twice. I know that is very challenging.

You had talked about your treatments as a child and then adult. How would you say those treatments were different from being a child being treated with AML versus that of an adult?

Alique: There comes a different level of understanding. My parents always tried to explain my care and have me involved in it even when I was a child. Doing things, such as helping me visualize my counts by using Cheerios as platelets and putting



them into a jar so I could see how many platelets I had each day and how those numbers were changing and what that meant for my body.

They really tried to figure out how they could explain it to me as a child at four years old in the best way possible.

As an adult though, I had just completed my PhD not even a year before my second diagnosis. So, I came with a great deal of health literacy that I think really was able to take me to a different level as a patient, as an advocate for myself, than most people actually have the privilege to do. And I'm very lucky for that.

I'm not sure how my doctors feel about the fact that my fiancé and I both come in the medical field and would do an entire lit (literature) review before any meeting to talk about any type of treatment. I think I gave them a run for their money with questions along the way.

I did feel very empowered throughout my treatment. I felt that I really was an active decision maker in all stages of my care as an adult. That really helped me take ownership over what was happening and help me deal with it in a different way.

Jesse: Absolutely! And, as you were saying, and we talked about this in past podcasts, being your own advocate goes a long way.

Alique: Exactly.

Jesse: This is your health. Educate yourself and question those doctors and get second opinions, third opinions.

And the one thing that stands out with me is, my heart always goes out to anyone who has cancer obviously, but with children it's a different challenge cognitively. You obviously, had a hand up when it came to knowing some of the protocols as an adult, and then also looking at what am I going to need to be my own advocate.

Alique: Exactly.

Jesse: Thank you so much for all that.

Alique: You know, when you're a child, it's really important to try and still be a kid to the doctors, to the nurses, to your family. They really tried to make it that we were kids as much as possible. From hosting water gun fights to holiday celebrations. And I think that's something else that's really different and was important during my childhood care.

Jesse: Well, it depends. I would also like to do that and I'm older.

Alique: Exactly.

Jesse: But, yes, definitely a difference.

Alique: I'm lucky for getting treated on the peds (pediatric) side both times. So, I did get a little bit of that even as an adult by getting treated on the ped side.

Veronika: And on the flip side is being trained in the peds side and then experiencing treatment in the adult side. Boy, is that two different worlds.

Alique: Yes, it is.

Veronika: For me, I used all the skills that I had learned professionally to help me cope with the adult world.

Alique: Yeah.

Veronika: Essentially trying to find the play, joy, and the normalcy in moments of extreme trauma because that's what cancer treatment is essentially.

Jesse: Absolutely!

Veronika: It's trauma.

Elissa: Yeah. Maybe the adult side needs to learn something and bring a little more joy to the adult side or a little more fun.

Jesse: I agree.

Elissa: Now our main topic today is focusing on the long-term effects that patients may have from chemotherapy. Veronika, you are now nine years out of your initial lymphoma diagnosis. And, Alique, you are now about 23 years out from your childhood AML diagnosis. While it's very common to have immediate side effects of chemo, like fatigue and nausea. Sometimes there can be effects that last for years after treatment. What side effects do each of you still have years after treatment?

Veronika: I find that when I'm trying to manage these side effects from chemo, the other thing that weighs on me is we always find something else. Things that aren't related to chemo. When you're trying to be in your best healthy self and you look at everything, it's just a lot to take in.

Right now, I have mild bone degeneration of the spine. I deal with high blood pressure, extreme fatigue, endocrine issues, I have hypothyroidism. My teeth are a mess from all of the throwing up that chemo induces as well as the bone degeneration.

So, those are the things that I currently deal with.

Elissa: Yeah, to be in your thirties and have all these long-lasting issues is difficult.

Veronika: Yeah.

Elissa: What about you, Alique?

Alique: Some of my issues are similar, but since I went through treatment as a child, they developed at a much younger age. I got diagnosed with high blood pressure when I was 12 or 13 years old, and got put on blood pressure medication, which is something that you never think of a 12 to 13-year-old having to deal with.

Elissa: No.

Alique: That's something that I know is a long-term issue that I'm going to face my entire life. Some of the drugs I was on as a child have pretty bad cardiotoxic effects. Since I was young, I've had to go for a minimum of at least annual echoes [EKGs] to make sure that my heart's okay. I also have dental issues with my teeth breaking because they were there when I was going through chemo as a child and it wears down the enamel and things like that. My teeth weren't even grown in yet.

I got diagnosed with different GI (gastrointestinal) issues, like IBS (irritable bowel syndrome), when I was also around 13, 14 years old, that they think was due to being exposed to this.

From my most recent diagnosis, I know it's only two years out, but now I've got bad neuropathy in my feet, and that's something that isn't going to go away. I think the issue that has the most prominent long-term side effects of my chemo that has affected me since I was a child is cognitive impairment. In my advocacy career and cancer career, this is actually going to be one of the first times I'm talking about it.

Since I was going through treatment when I was four and my brain was developing, it caused the myelin on my brain to crinkle. Because of that, I actually got left with a lot of different learning disabilities related to executive dysfunction, language, numbers and math. And growing up was really hard. I was always in special programs, I had an IEP (Individualized Education Plan), I had specialized tutors.

I remember in grade school and high school, like there was a time where my teacher were saying they didn't know if I was going to be able to succeed academically. My mom and my family never believed that. They just kept getting me specialized services, kept getting me special tutoring, taught me how to learn for my brain. When I entered that special education program in high school, things started to change for me, and I started to learn that I actually could learn.

Being able to actually have the support that was necessary to overcome these cognitive impairments, I think is able to contribute to my long-term success. You know, if you would have told some of those teachers, and even younger me, that I would be here with a master's and a PhD with these cognitive impairments, I don't know if I would have believed you because for so much of my life it was being hammered into my head that, you have these learning disabilities, you're not going to be able to be successful in this way. I think it just really shows that, if you have the proper supports in place, you can overcome things that people think you won't ever be able to.

Veronika: I have cognitive issues too. Focus, memory. I, too, have a PhD, and I got it post cancer and post treatment. And it was different. It was so hard to focus, to read, to sit. My peers could sit for hours and hours and type and type. And after an hour or two, I got to go. I can't look at this screen anymore. And I, too, love to learn, and it was night and day. Essentially, you have to relearn how to function in the world which was not built for you. Or a world that won't recognize the adaptation that you need to be able to succeed.

Alique: So, cancer related cognitive impairment is actually one of the most common long-term effects that patients experience.

So, 70% of patients who are going through treatment experience some form of cancer-related cognitive impairment. At least 35% of those patients experience cancer related cognitive impairment up to a year after and longer beyond treatment.

Currently, I'm running a program right now for patients with cancer related cognitive impairment that goes over behavioral strategies on how to try and improve these things.

I went through cognitive testing again after my second diagnosis, and we did find more cognitive deficits and things like that related to the second round of treatment. There are different kinds of coping strategies that people are able to use for these, but

there isn't a pharmacological intervention, so it's not something where you can just say, "Here's a pill, this will help your cognition. This will help your focus." We haven't gotten that far in the field yet. We haven't been able to figure out what are the actual factors that contribute to this cancer related cognitive impairment because, technically, chemotherapy isn't supposed to cross the blood brain barrier, specific chemotherapies, like most of the ones that people take.

And so, it's kind of an issue that's perplexed academics, researchers and clinicians for a very long time now but didn't really start to gain any traction in the field until the late nineties. It's an area where we really need more focus as survivors and clinicians.

Jesse: Well, before my next question, I just wanted to say how proud I am, and I admire you both for overcoming such adversity. And then, on top of that, helping others to make it better for them.

Alique: Thank you.

Jesse: Alique, this is a question for you. Since you are going through your second AML diagnosis, did this new round of chemo make your prior side effects worse or more intense?

Alique: Yes. When I was going through treatment, there were times with my cognition that were really scary for me. I remember my partner looking at my mom and saying, "Is this going to get better?" I was having a hard time finishing sentences. I was having a hard time with word recall.

Luckily, a lot of that was due to the acute effects of the actual treatment that was going on at that time, and I have been able to return to work.

But it's scary when things like that are happening to your brain and you don't know how to control it. But I think you can learn how to cope. And you can learn strategies that can try and make these things easier that can help you in your daily life, different

behavioral techniques. But, no, I don't think you can go back to that level of functioning that you once had.

Veronika: I don't think you can go back to that old you. You have to find an acceptable version for yourself moving forward. A version that you're okay with, that might be better in things that you didn't do before your cancer diagnosis.

There's a lot of pivoting that has to take place. In treatment, that's all we did. There was always something new, there's was always a different side effect. We talk about how awful it was, but we did learn skills that other people don't have as cancer survivors. And I think, as cancer survivors, we need to do a better job, of celebrating what we've become is not less than what we were, but it's new.

Alique: Right.

Veronika: We are different, but that is not less than.

Jesse: Yes.

Veronika: Anytime that I can provide the tools or new avenues to help people share their story, to help them fundraise for a cause, to help pass legislation, those are things that we didn't do before this cancer diagnosis. So, these are new exciting things that we have to pivot.

Jesse: Well said.

Lizette: Yeah, definitely. You learn different things and a lot of cancer patients that I have met, most have what I call grit. You rise above. And it's because what you're saying, Veronika, that's what you're doing when you're actually going through active treatment.

You went through something that not everybody in this life has gone through. And looking at both of you, it has made you stronger in different ways.

Veronika: And it doesn't mean that I don't take a nap sometimes. The reality is that you just have to work it in to your normal, everyday life schedule. It just becomes something that's worked in. It's my normal.

Alique: There's so many different things that change with long-term survival, and there's so many things that have just become part of daily life. But throughout my life, one of the things that's always been the hardest for me to talk about was growing up with this level of cognitive impairment and learning disabilities and having to have these IEPs [Individual Education Plans]. And I left out my visual impairments. I lost my right eye when I was four years old because I went septic during cancer treatment. So, I'm blind in my one eye and I have a prosthetic.

And those two things have always been something throughout my remission and my advocacy where I've almost held those cards close. I felt like there was a stigma attached to it.

But after going through it the second time, working in this space now, and really seeing it more of as an adversity that's overcome, growing up, it was how Veronika said, very much like, I thought of it as a less than side effect. Something that I was just going to be left with forever that was always going to leave me as being less than.

But after going through it the second time and working in this field and learning how to learn for myself, and actually seeing how I overcame all of that against the odds, it's brought a different level of pride now. And, that pride, it's given me the ability to be able to talk about that on a platform like this because this is something I never wanted to say to the world before. It was one of those things you always keep close to your chest because you don't want people to think differently of you.

Lizette: You're not letting that define who you are.

Alique: Yeah.

Lizette: Both of you with coping and just your education and your success. That's something that I do want to highlight to folks. And like you said, Alique, to look at you and know that even though somebody's telling you, you can't do something, that may not always be the case.

I know that you both have alluded to what you have done working with these side effects. Do you work with your doctors to manage your side effects or have you just been able through time to come up with different techniques?

I know that a lot of folks are really interested in knowing some of the techniques that have worked for you with your side effects.

Veronika: Absolutely! So, for me, and most who have complained about fatigue to their oncologists or their physicians, sometimes you get the recommendation, "Well, you need to exercise." Tell a person that's extremely tired. And, for me, fatigue is just bone weariness. When I'm tired, I've worked 16 hours, and I start to yawn, that's tired. That's normal cause and effect. You're starting to not be able to focus, you're yawning. For me, that's when I know I'm tired.

Alique: Right.

Veronika: When I wake up fatigued it's different. When you've slept 10 hours and you get up and nothing wants to move, your brain's not focusing with what your arms are doing, and you read the sentence 10 times because it's just not computing, essentially. That's fatigue. If you get moving and you get everything flowing, that helps a little bit. So even though it feels like it's the opposite, it does work. I wear a Fitbit® religiously, every day I get 5,000 steps automatically. On long days, which is every other day, it's a 10,000 day. I need to move to be able to manage that fatigue. But I have mild bone spinal degeneration. My joints aren't great. My spine's not great. I saw my primary care provider and I said, "I need PT (physical therapy)." I've been doing PT for the last six months because we fixed that problem with the muscle but, really, I have no muscle in my back. I need more muscle in my legs. And I need

supervision because I'm a klutz. And it makes me feel more comfortable, and I'm accountable to go, but I'm also lucky enough to be able to afford it.

Alique: Right.

Veronika: Which is the other issue. My primary doctor that I see regularly is my primary care physician. She manages all of my extra stuff. And then I see every specialist under the sun too. She will say, "I'd like their opinion, you're a little bit complicated." Another doctor, another appointment, and more importantly, another copay.

Alique: So, I do want to hit on the exercise point because, different doctors recommend exercise for different things. I am part of a cancer exercise wellness program, and I do supervised exercise as well. Part of this is because the chemotherapy I'm on makes me not develop muscle the same way that other people do. Being part of this program, it ensures that I exercise 180 minutes a week at minimum, and I have to say, I was one of the people who is like I'm too tired to exercise, this is ridiculous. But they recommended it for my fatigue, they recommended it for my neuropathy, they recommended it for my cognitive impairment, and at that point, I was like, okay, these are three of the biggest issues that I'm complaining about, I might as well try this one thing that they're saying could help address all three. And I really have noticed a huge difference. If I make myself go and I do it, I attribute my level of exercise as one of the only reasons I'm able to have enough energy to complete some of my workdays and to continue functioning. Especially when I'm on my chemo weeks.

I really didn't believe it. I have to say, I really was like, "you are crazy telling a tired person to go workout." But I really have noticed a huge difference in my overall quality of life, my cognition, and my fatigue when I'm doing those recommended levels of moderate aerobic activity.

Veronika: I don't have access to that program in the city that I'm in. You might not have access to that program.

Alique: Right.

Veronika: It's on us to cobble together something that works. I don't have access in my city to cancer rehabilitation, where you might have access to that in your city.

Alique: There are some great resources online for cancer modified exercise services though. Places such as the Gathering Place, if you have a cancer support community in your area, cancer support community offers cancer exercise wellness. Gilda's Club offers versions of that. And a lot of these have modifications for cancer patients and survivors that help keep in mind things such as balance issues, neuropathy issues, strength issues, and they make those modifications.

So, especially places like the Gathering Place where you can do it live online instruction with a trainer who is literally watching you as you're doing it. It helps people get access where they don't have those kinds of programs like that right in front of them in their community.

Veronika: Yeah. As I already said, I'm the klutz. We really need to do that stuff under the care of people who actually know what they're doing.

Alique: Yeah.

Veronika: And so that's very important to be monitored or to follow a program that has been sanctioned by someone that you can talk to about exercise. And utilizing what you have. If it's PT (physical therapy) in your community.

I found a great one. And eventually we got to the point she said, "Well, what's your goal?" I said, "Well, my goal is to run." And she said, "Oh, I thought your goal was to fix that muscle spasm. "Yeah, like I want to fix that, but long-term, I want to be able to have enough flexibility in my hips to be able to feel comfortable jogging." Then I

start talking to survivors and I say, “What are you doing? Do you have a dog? Do you walk the dog? Do you go out and get the mail?” We don’t give each other enough credit for the stuff that we do. Again, it goes with that less than mentality.

Alique: Right.

Veronika: We need to give ourselves credit for what we’re accomplishing, and then we build a little bit, and build a little bit.

Alique: For other issues, the exercise that’s supposed to help with fatigue, it’s supposed to help with cognitive impairment. Some of the issues that we face in our daily lives aren’t things that necessarily can be fixed with medications.

Before I was talking about how I deal with really bad neuropathy now. Yes, there are nerve medications I can go on. Do I want to be on another medication at this time on top of all of the others? I’m trying to avoid it. So, I’ve been doing things such as acupuncture which actually has been really helpful for my neuropathy and for my nausea and for my IBS. So, talking with your doctor or finding a doctor in your area who does things such as functional or lifestyle medicine or integrative medicine, can be helpful as an additional way to find supportive services.

These things aren’t necessarily able to be fixed just through a doctor’s care. A lot of these things you have to have a very active role in. For cognitive impairment, a lot of it comes down to things like doing lists, having reminders, having different systems in place to help you remember things, taking breaks; and prioritizing those things.

Another huge issue that can exacerbate these long-term effects is loneliness, so making sure that you’re getting enough social connection. Loneliness has very similar rates of different components of mortality as different chronic conditions do. And how people’s lives have to change to adapt and things that they do now that they didn’t do before, and where that isolation can come in, and making sure that you’re addressing that as well.

And a lot of these things are behavioral adaptations. The things like the lists and the different reminder settings and the breaks, those are things that I've built into my daily schedule now.

And habits don't happen fast. Sometimes habits can take 10 weeks or more to form. So just getting in the habit and starting somewhere is a really important component of this and deserves to be celebrated even if you are taking small steps in forming these habits because one day, they become a part of your daily life and you don't have to think about them as much anymore.

Always give yourself grace because things are hard. Overcoming these long-term effects is hard and maybe these things can make it a little bit easier in the long run.

Veronika: And you're not alone either.

Alique: No.

Veronika: Cancer survivors are dealing with these things on a daily basis. Some people are dealing with them more so than others. Everybody has a different personality, everybody learns differently, everybody can pivot in different ways, but we're all here. And I know it's so tiring to fight for what we need. You are not alone.

Alique: No.

Veronika: The other thing I want to say, we've been talking about our PhDs, and I think Alique would agree with me, you don't need a PhD to be able to advocate for yourselves.

Alique: No. As a survivor, too, especially when I started to hit the 20-year mark of survival, I started to notice that when I would be asking if something was due to my chemotherapy, or if this could be a long-term effect of the chemotherapy I went through as a child, how my doctors' reacting started to change. They started to say, "Oh no, you've been out of treatment so long, it's almost like you didn't even get



treated at all. We're not worried about long-term effects anymore because you've been out of treatment for so long this isn't a concern."

But if you believe that that's something that could be happening, you need to advocate for yourself in those roles. I was told about four months before my diagnosis in August that there was no chance of my cancer ever relapsing, just to relapse in March.

So, you know your body best. Just because somebody is saying that something isn't a long-term effect, make sure you check on that. Make sure you advocate for yourself because a lot of the times, we don't really know that much about long-term effects. Clinicians don't know that much about long-term effects.

If you are a survivor and you have access to a cancer center where you can get a survivorship visit, where you can get a survivorship care plan. Please do it because that is going to be one of your best resources for tracking your long-term effects, for tracking things to look for that could happen related to your chemotherapy, for having that care plan always in your back pocket so if you transfer doctors, if you transfer cities, you still have that information, and you can still advocate for yourselves based on your care plan.

Elissa: Yeah, the survivorship care plan is so important. At LLS we have a survivorship workbook, one for young adults, one for adults, and then for peds as well. And you're right, you do need something to carry around with you because you will switch doctors throughout your life, and it's good to have that written down.

Now that brings into our final question. On our patient podcast homepage, we have a quote that says, "After diagnosis comes hope." What advice would each of you offer to patients who may be suffering from long-term effects to give them hope for the future?

Alique: I think being able to live a life that's whole for yourself, even beside these effects, and not always letting them get you down. Take the time to mourn for it. I'm

still trying to figure out things I can do, little things every day to make these things easier, to help overcome them. But I think it's that grit and giving yourself grace to know that maybe this is a bad day for some of these symptoms, but not every day is a terrible day for these symptoms. Not every day. Some are better than others.

Veronika: For me, my hope is that I leave something behind that's, that's worth it. That's what keeps me going. That I'm leaving essentially a legacy behind. That there are things that I'm putting on this earth that'll help other people, whether that be cancer survivors, whether that be my second love of teaching, the arts. I used the skills that I have, the talents, the experiences that have been bestowed upon me.

That gives me peace. I don't know about hope, but every day I try to find some peace with what I've suffered through, what I've added to this world, and that I'm finding the joy every day. That I'm creating opportunities for other people to find joy every day. To do what I love, which is education and learning. So that's where I sit trying to leverage all of these things to be able to make sure that I live a life. Sometimes I skip life steps and that okay too. You just have to give yourself grace, find peace.

Elissa: Well, thank you so very much, Veronica and Alique, for joining us today. I just really love how even though both of you have had these difficulties for many years, look what you've been able to do with them. I think that it shows your strength and your determination to have a good life. Both of you going for your PhDs after cancer and dealing with the cognitive decline and other issues, I think is so impressive. And it is so important to give yourself grace for all the days that it's not going right, and things are not okay. And it's okay to not be okay.

And, also, to allow yourself to grieve that prior life, that life before cancer, that life before all of these side effects came up. And find a way to find that peace, grow in your life and find joy in some ways.

So, thank you so very much for being here with us today. We just really appreciate you both sharing your stories.



Jesse: Yes, thank you.

Alique: Thank you for having us.

Veronika: It was a pleasure.

Elissa: And thank you to everyone listening today. The *Bloodline with LLS* is one part of the mission of the Leukemia and Lymphoma Society to improve the quality of lives of patients and their families. To help us continue to provide the engaging content for all people affected by cancer, we would like to ask you to complete a brief survey that can be found in the Show Notes 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.

In addition to the survey, we are excited to announce 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.

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 information about managing side effects at LLS.org/Treatment. 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.