Episode: 'Hodgkin Lymphoma Part 2: Struggles of a Young Adult with Cancer'

Description:

Join us for Part Two of a special two-part series as we speak to Dr. Christabel Cheung, a two-time Hodgkin Lymphoma Survivor. In this episode, Christabel talks about her extraordinary struggles as a young adult with cancer, such as living alone without family support and having high healthcare costs. She also delves into the health disparities, racism and racial insensitivity that BIPOC (Black, Indigenous, People of Color) patients experience. Be sure to listen to Part One first to hear more about Christabel's journey with Hodgkin Lymphoma as a Young Adult.

Transcript:

Edith: Welcome to The Bloodline with LLS. I'm Edith.

Elissa: And I'm Elissa. Welcome back to the exciting conclusion of our special two-part episode on Hodgkin's Lymphoma and Health Disparities with Dr. Christabel Cheung. If you missed part one, be sure to go back to the last episode and listen to that one first. In the first episode, we heard all about Christabel's cancer journey as a two-time survivor of Hodgkin's Lymphoma, her work with young adults and health disparities and the difficulties of going through cancer as a BIPOC patient. As we finished the last episode, Christabel was sharing with us the importance to her of sharing her story as a young person with cancer. Let's continue…

Dr. Cheung: So basically, it's really important for me to get the story out there of what it's like as a younger person to go through the cancer experience twice for an extended period without the assumption of support from family members, which is such an important assumption that our healthcare system relies on.

Elissa: They absolutely do.

Dr. Cheung: How many times, Elissa? I mean think about when you were discharged, it's assumed that someone's going to come and pick up your personal belongings bag.

Elissa: Oh yeah.

Dr. Cheung: When you get admitted, it's assumed that someone will be there to like take your wallet away from you.

Elissa: Yeah. I drove myself when I was neutropenic to the Emergency Room. It didn't go over well with my doctor, but. You know, they assume that somebody will be there, and somebody will take you and you always have a ride and that's just not the case for so many young adults who live on their own, who maybe don't live with somebody who they know very well, live with roommates who might not be supportive. And it can be very hard with young adults, particularly ones who are not married and live on their own and they're doing their own thing. And for you, I mean that's a huge chunk of your adult working life that just got taken in a totally different direction.

Dr. Cheung: Yeah, yeah. And it's going to sound awful to say, but cancer has been an awful thing to happen twice. At the same time, it's not necessarily the worst thing that's happened to me. Living out of my car as a 16-year-old in the suburbs of Detroit was an awful thing because I was young enough that this is why age matters in this way, but as a teen, I wasn't knowledgeable enough about how the world worked to know that there was hope. And so, I was lucky in the sense. I think my experience of being a disenfranchised, unhoused young person really points out the influence of socioeconomic difference. I came from an upper middle-class family and background. I had friends' parents that helped me. I stayed on people's couches when I wasn't living in my car and, you know, going to soup kitchens and all that stuff to get food. I knew where the soup kitchen was because I had volunteered there-

Elissa: Wow!

Dr. Cheung: -in school. So, I knew, and I knew enough to go drive to Detroit to get food and then come back and park my car in the suburbs to sleep where it's safer.

Elissa: Yeah, know where to go.

Dr. Cheung: And so, yeah, exactly. So, it's things like that that socioeconomics does make a big difference and I feel very lucky and blessed to have gone through these experiences and they've made me the person that I am, like it or not, right?

Elissa: That's what everybody says.

Edith: Yeah, exactly.

Elissa: It'll make you the person that you are and.

Dr. Cheung: That's what we have to say about the pandemic, yeah.

Elissa: That actually brings me to a really good quote that I loved on your blog and I think you were talking about Dr. Zebrack and his family at the time. And you said, "You can live long enough and good enough for the people around you to stop saying that your cancer is the most interesting thing about their relationship to you."

And as a young adult cancer survivor or current patient, who hopefully has many, many more years to live, what prompted you to write that quote and what does it mean to you in your own life now?

Dr. Cheung: I am just blown away by Dr. Zebrack and his family, his wife, Joanne, and their daughter, Sierra. They came into my life at such an influential time in terms of survivorship and-I wrote about this conversation that I had with Dr. Zebrack's wife, Joanne, and it, it just moved me so much.

But I remember when I first started dating again, you know, and the first guy that broke up with me made me so happy-

Elissa: You don't hear that very often.

Dr. Cheung: -because I was like I'm healthy enough where someone thinks they can break my heart, and it's okay. Yeah, this is living. I don't just make people sad and people don't just feel sorry for me and take care of me. He treated me like any other – I don't know. There're problems there, right. But it felt so good to just have like a normal social experience, but I think what's difficult sometimes now and maybe this happens to you as well, Elissa, is that I meet new people in my life, and I've gotten feedback that it's just hard to believe that you were ever really sick.

Elissa: Yeah. You don't look sick, right. That's what you hear all the time.

Dr. Cheung: Yeah, and I'm like do I need to show you my like 12 different scars or like?

Elissa: Yeah, yeah.

Dr. Cheung: So, what I do in my advocacy is I actually use the picture of my first CT scan. And I don't tell people that it's me, but I start with it and I show them, and you see all the tumors and it's all crazy. And I was just like, you know, "For those of you that haven't seen a CT scan, this is what Stage 2BE Hodgkin's lymphoma looks like. It was my very first one." And I was like, "Yeah, this is before I got super bad." But at the end of discussion, then I'll say, "That was me." It helps put a face on the cancer experience. I think that there are also the late effects of cancer are difficult to explain to people in your life as particularly the cognitive stuff.

Elissa: So, once you're done with treatment, then you're done.

Dr. Cheung: Right, like.

Elissa: And that's often not the case.

Dr. Cheung: Right, yeah, and I still have extreme fatigue. My short-term memory sometimes fails me. So, banter in conversations can sometimes be difficult. I'll remember the themes of what you said to me, but I can't repeat verbatim sometimes-

Elissa: Right.

Dr. Cheung: -you know, what is said to me. That kind of thing. A nurse friend of mine, my Dr. Auntie Pat, said to me at one point 'cause I had just started his research project with her, and I said to her, "Be honest with me. How bad is my short-term memory?" And she was like, "It's not bad at all." And I was just kind of like, "Yeah, but yesterday I forgot this and had to be reminded," blah, blah, blah. And she said, "Honestly, if something's important, it'll come back to you."

Elissa: Yeah.

Dr. Cheung: And I do all the things of like, I take tips from what I used to tell older adults. Like, "Don't write things on Post-its. Use a spiral-

Edith: Right.

Dr. Cheung: -notebook that's bound." You know, things like that, right. But I think that sometimes new people in my life think that I'm just flaking on going to an event or something. They don't realize it's actually fatigue or that I'm just making an excuse for not listening to them when it's a short-term memory flub and in combination with fatigue or something like that. So, I think that's difficult in survivorship.

And then in addition to just like the unknown because I know for my disease, and maybe this is true for you as well Elissa, I'm the first generation of two-time Hodgkin's lymphoma survivors who have had the treatment regimen that I've had, and 30 years earlier I would be dead.

Elissa: Yes.

Dr. Cheung: So, you know, that's why we're experiencing the cardiotoxicity because I'm living long enough to experience it. So that's the major difference between younger adults who have a cancer diagnoses compared to the older is that older adults won't live long enough to experience the late effects of the toxicity exposures that they've had, right.

Elissa: Yeah.

Dr. Cheung: But we are now living long enough to experience that and what does that mean for us.

Elissa: And I think what's nice about that is that we can take that into the future research. Say, "Hey, all these people are experiencing these late-term effects. How can we change the treatment? How can we change the medication to make that better?" because they are living longer. And you're seeing that in pediatric patients, you're seeing that in young adults that they're living 20, 30, 40, 50 years after their treatment and they're having these effects come up that we just didn't see 20 years ago because instead—

Dr. Cheung: Right.

Elissa: -they probably passed away or they were older adults, and it does definitely bring up a good point that there are those late-term effects that we're just now starting to see.

Dr. Cheung: I think precision medicine is advancing so quickly and so well that I think basically gone are the days of just like mustard gas for everyone. Everybody mustard gas, you know.

Edith: So, Dr. Cheung, on our patient podcast Home page, we have a quote that says, "After diagnosis comes hope." And based on your cancer journey and your professional experience, what would you choose to complete that sentence? "After diagnosis comes."

Dr. Cheung: I'm a realist, and so I would say, "After diagnosis comes shock and fear." I think immediately it's the shock of it. For myself when they told me, I'll never forget. It was on my cell phone. You shouldn't get your diagnoses on your cell phone, but so many people do on my cell phone. "We believe that you have a type of cancer called lymphoma." And my response was, "A type of cancer is not like cancer cancer, right?"

So, I think immediately shock and denial and then just fear. Just fear because, before cancer, my first-line treatment was six months of ABVD chemotherapy. And so, before that, having a cold for longer than two weeks pissed me off, you know, so like to say to me, "You're going to be sick for six months," you know, and it's actually way longer than that, but I could not even wrap my brain around what that meant. And then people were using words that I didn't understand. When they said that "We found something significant on your scans," I was like, "Cool." Like I don't know.

Edith: Like after you get a test result, it says, "Unremarkable." And you're like, "What, what does this mean?"

Elissa: Right. That helped.

Dr. Cheung: Yeah, I didn't understand that being medically interesting is actually awful. So.

Elissa: Yeah.

Dr. Cheung: I actually was talking to another cancer patient who said, "Yeah, I remember when I first got diagnosed, they kept telling me, 'Go to imaging.'" And she was like, "What is imaging?" And she was a PhD candidate at the time. She worked, she was a PhD candidate working in biomedical engineering actually, and she didn't know what imaging was. I don't know who's supposed to know. So, I think that a lot of times how we take care of young people right at the point of diagnosis and communicating that message, it builds the patient trust that can last and has the potential to last across their entire patient treatment experience. It will reduce treatment nonadherence, it will reduce the questioning your advice in other ways, and it will just overall improve their relationship with other providers as well.

I still to this day never met the physician who communicated my cancer diagnosis for me. He was pinch-hitting for his intern who was the person that I had seen actually in the visit. And my story is not uncommon. Many people get their diagnoses on their phones and my cell phone dropped the call in the middle of what he was saying, which didn't even matter because I wasn't even listening.

Edith: Right. So, it did you a favor.

Elissa: Just kind of went into shock at that point.

Dr. Cheung: Exactly. But what was dangerous is that I have a blackout in terms of how I got home that day. I knew I got home from downtown to my apartment, but I have no idea did I walk and take a bus. I have no idea how I got there. I have no memory of it.

So, I think that when we don't take care of each other in terms of the shock and awe of a cancer diagnosis, we really run the risk of young people not trusting us later on. And so, building patient trust, particularly for individuals who come from communities where there is a huge distrust of the healthcare system to begin with and we've been raised with that distrust, and then you treat us that way, then it just underscores reasons why we shouldn't trust. So, thank you for asking that question, Edith.

And there's so many, steps to get to before you ever get to hope. I don't even know if I've gotten to hope yet.

Edith: And that's fair.

Dr. Cheung: Yeah, I think that there's a lot of pressure to say that you have hope or you believe in this and that, but I think for a lot of us we're just getting by one move at a time.

Elissa: Sometimes it's just doing what you have to do to survive. And everybody who's involved in the cancer community has seen people just completely break down after treatment. You're going in all the time and then they're like, "Okay, bye." And it's so normal to just completely break down and, it's because you just, you've been doing what you have to do to survive. And then what? And then what do you do with your life? What do you do with your day? How do you keep going when people don't understand what you're going through, what symptoms you're still having? There's a lot to be said about that.

Dr. Cheung: Yeah. During the course of your treatment, there is no safe space for you to really be with the reality of your emotions and all of that. It comes so much later. Because of the politics of being a patient, when I was dependent on nonfamily help you can kind of be rude to your family members sometimes and they'll still help you.

Elissa: Yeah, not so much to friends.

Dr. Cheung: Yeah, you can't be rude to friends and expect them to want to sign up again for your food train or whatever after you told them to like get lost, you know. I managed it on a spreadsheet in a private website and everybody had to sign up and everybody had to know to like mask up and do all these things which, you know, very foreign at the time. This is pre-COVID. And everybody had to know my allergies and all of that stuff. It was just a lot to manage and, like I said, your family of choice are moving parts. Sometimes people, end up being more harmful than helpful and so then you have to not have them help you anymore and that's challenging to manage.

I felt like being a patient was more than a full-time job. And when I wasn't doing that sort of, people management, then I was filing appeals for health insurance denial of my medications. I remember Mepron was a medication that I needed to prevent a life-threatening pneumonia post-transplant process and it was $1,500 for a one-month supply. And-

Edith: Wow!

Dr. Cheung: -the health insurance wouldn't cover it. So, I actually found a pharmacist who was kind enough to give me two month's supply while I filed the appeal that it took less than a year though, which is kind of good. But I would say that even now every year now in survivorship I have to file an appeal for something that was denied, whether it's a CT scan or, or what have you. And when I was in the bone marrow transplant process, they wouldn't approve radiation and so it actually took three sort of nasty letters from my oncologist who finally cited data to say, "You've actually decreased her chances of survival by this now."

Edith: Wow!

Dr. Cheung: And, then they covered it. And I remember I just didn't understand it as, you know, being so naïve about healthcare at the time. I would get on the phone with these customer service people, and I'd be like, "Do you think I want a PET scan?" Right?

Elissa: "This is not what I want in my life. I'd rather not have cancer or any of this."

Dr. Cheung: Right. Like, "I don't want it either. You don't want me to have it, I don't want to have it, but I need it." It's made me want to do research in this field more so that we have the data to support the experiences of these individuals so that we get taken seriously 'cause I really see the power of data and it really informs our practice in every area of cancer survivorship.

Elissa: Yeah. And for some reason it seems that a lot of doctors, primary care physicians don't seem to recognize that young adults can get cancer and they can get it very often. I think what, are we at about 70 or 80,000 a year of young adults that get diagnosed with cancer. And it is very much seen as, you know, a children's disease or an elderly disease and young adults seem to be left out of the conversation. And that goes into insurance companies and everything as well that they don't listen.

Dr. Cheung: Right, right, and so like to your point about, okay, so it's like between I think it's 77,000 new AYA cancer diagnoses each year. So, it's about 5% of the 1.7 million, right, cancer diagnoses overall-

Elissa: Yeah.

Dr. Cheung: -each year. And, and so people often say, "Well that's a, such a small percentage," but it's still six times more than the number of pediatric cases. And, if you compare that to it's still 40% more than the number of new HIV diagnoses each year. So, it's a sizeable population. It's just that it's a small proportion of the overall cancer population. But if you look at the AYA population, the types of diseases that we get are distinct. There’re 24 most common diagnoses amongst AYAs. And the kinds of cancers that present in AYAs cannot be screened for in the ways that older adult, you know, the typical prostate, colorectal, breast, lung. Those are typically the four that people are screened for later on in life. Those are not the most common cancers in young adults.

Elissa: Yeah.

Dr. Cheung: There is no screening for Hodgkin's lymphoma. You have to do imaging; you have to do blood tests. It's this calculus of all these different moving parts.

Elissa: Yeah. Unfortunately, there's no screening for blood cancers and it's very difficult, you know-

Dr. Cheung: Right.

Elissa: -it takes somebody having symptoms or having something else and then going in and all of a sudden getting a blood test and finding out that you have a blood cancer. Yeah, it's very different than, than tumor cancers where you may feel something or see something or not necessarily have those symptoms but have a big tumor.

Dr. Cheung: But the challenge is that it is extremely rare to get cancer in this age group, so can you even have something in the electronic medical record that pings a physician to say, "Check for this, check for that, check for that" because it might be a waste of their time for their entire career except one time. So, I don't know what the answer is to that. They're probably getting pinged for everything in the medical record too, so they're probably tired of that as an intervention on anything. But I think I think that we need to have that conversation of so how do we screen for it and is it just a greater awareness amongst physicians that it's a possibility because in particular for breast cancer I've heard a lot of young women with breast cancer receive feedback from their physician that they're just, they're too young for breast cancer, don't worry about it.

Elissa: Oh yeah. My friend got diagnosed with breast cancer at 24 and she was absolutely told she was too young for this. Yet she had a tumor the size of a grapefruit and got it removed right before her 25th birthday. And so, I think that a lot of physicians just generally don't think about that being something on their radar, that cancer is on their radar for this young adult.

Dr. Cheung: Right. I'm so sorry to hear that about your friend, that's awful. But also, for someone to receive a breast cancer diagnosis at that age is so different because the host biology is so different from older adults that get an early-stage breast cancer diagnosis often because-

Edith: Right.

Dr. Cheung: -they are screened for it, right. So, it's such a different experience and so much more life-threatening with a tumor that size. That's incredible. Yeah.

Elissa: Yeah. And think about Chadwick Boseman. He had colorectal cancer as a young adult. And that's something that for the rest of us is almost unheard of. You know, they don't start screening for it that early, yet here it was it happened and then he passed away from it. I mean I feel like that should scare everybody our age that, gosh, that's actually a possibility. Something that, we're not even going to get screened for another 10, 15, 20 years yet here is somebody who got it and passed away from it. And how do you even ask to get screened and get approval to get screened? You know, what symptoms need to come up to be able to get screened?

Dr. Cheung: Right. In the December issue of *Elephants and Tea Magazine* – are you all familiar with *Elephants and Tea Magazine*?

Elissa: Yes.

Edith: Ah, I love *Elephants and Tea*, yes.

Dr. Cheung: The young adult cancer magazine. So, I wrote a couple articles in the up-coming issue. One of them is called, it's entitled "Black Girl Cancer Magic." And it's the friendship story of my friends Iman Perry and Chellese Parker, and we lost Iman to colorectal cancer. And it's just a very, very beautiful story of the two of them. Chellese is also herself a cervical cancer survivor and, and very active in the BIPOC AYA advocacy community as well.

And then the other article is more of, it's a Q&A sort of panel in writing that I did. The title of it is, "Practically Speaking Antiracist Survivorship Advice From and For BIPOC Patients." So, I speak to three of my young friends and it's me moderating a discussion with them about their experiences. And what's, I think, beautiful about it is that we really talk about the intersectionality of different identities, different individual markers of difference and also the intersectionality of marginalization.

And so, I think it breathes nuanced complexity to this discussion I think that it's been so missing in just the field of medicine at large too. I think that they are also in their infancy of addressing issues of race, gender equity, and socioeconomics and all of that. You know, all the things that make everyone uncomfortable we wanted to put it together into a discussion. So, I hope that people can check that out in the next issue.

Edith: We definitely will.

Elissa: What's really nice is that it's so much coming to the forefront this conversation finally about, you know, racial and health disparities and health equity. And that has all come to the forefront which I think a lot of people didn't pay attention to enough before or didn't realize or didn't see it. And it's a great time for those greater conversations to really happen so that more people are hearing about it and seeing it and seeing what actually happens.

Dr. Cheung: Yeah. And I think for me personally, you know, having been a long-time activist in the communities that I identify with, I think that I often felt that when I was interfacing with the mainstream, it'd be like, "Oh there she goes again Christabel talking about race." But now it's, people from-

Elissa: Now it's accepted.

Dr. Cheung: -the dominant group wanting me to talk about it. And sometimes it's not appropriate, and I think it's important for everyone to recognize that this racial awakening is happening amongst nonblack communities-

Elissa: Yes.

Dr. Cheung: -that it's nonblack communities that are coming to the awareness and having these conversations and finally listening sometimes. So, I think that it's interesting because there's a lot of performative stuff that happens that it seems to be self-serving that I sort of had this conversation with my younger advocate friends about how we need to conserve ourselves because we're being asked commonly to without compensation, use our cancer stories and essentially our skin color to help make the case that X or Y organization is not racist.

Elissa: Right.

Dr. Cheung: Right? What you're talking about these meaningful conversations like really need to happen and it'll produce results that are actionable and can influence longstanding racist structures and that’s the change that we want to see not just more airtime. I often think of the more airtime stuff like giving equal airtime as just token liberal multiculturalism.

It's just kind of okay, we honor your holiday, and you honor our holiday. We give space for your religion, you give space for mine, that kind of thing. But it's more than that. We're talking about social justice.

Elissa: Yes.

Dr. Cheung: We're talking about health equity. And the data is there. We all know that disparities have existed for a very, very long time. And so now which is what made me develop this antiracist patient in engagement and research line of inquiry. It's because I want to look at what I'm doing myself, how I engage patients who are BIPOC AYAs are particularly vulnerable. The experience of racism is a trauma. It's acknowledged as an expanded adverse childhood experience that all young people of color move through.

So how am I going to be a good sort of steward of their survivorship process and not be exploitative or opportunistic? I think for a lot of our young people it's asking the same questions over and over again in the way that you would if someone is telling you that they're questioning their gender in your first discussion with them, you check back with them later. You wouldn't just be like, "Okay."

Elissa: Right, just let it go.

Dr. Cheung: "But for now this is what you are, right." You know, and then and, and walk away. Like that would be completely irresponsible.

Elissa: Yeah.

Dr. Cheung: So, I think same goes for the salience of, of race and identity and in other areas, right. And so, I think that we need to each look at our own practices and how we move about in our professions and not just think of it as like, oh, well I'm going to volunteer my time here. I'm going to throw up a black square on my Instagram.

Edith: Right.

Dr. Cheung: I want us all to change how we are. And I'm participating in it. I'm not just saying other people need to do it.

Elissa: And I think it takes checking yourself and checking your actions and your words and really thinking about them and how it affects other people and what you can do as an individual to make change.

Dr. Cheung: And, and I haven't really connected with many other BIPOC AYA patients who are Asian and moving through treatments across COVID, but I mean we've all been called the Chinese virus through all of this. We've been heckled on the street. We've been mistreated. So, the anti-Asian sentiment that is synonymous with COVID-19 is something that has really impacted me personally. I had this older woman actually throw a shopping cart at me early on in COVID and yell at me to get away from her. And it shocked me because I haven't felt that kind of, you know, I'm not new to racism.

When I first moved to the Detroit area, as an immigrant, we were oriental. We didn't even get to be Asian yet. So, you know, I was raised in that context. I've dealt with it and it was funny because when she threw it at me, I turned because I didn't think it was for me. I didn't.

Edith: You're probably-

Dr. Cheung: And she's yelling at me.

Edith: -"Like, oh who's the person next to me?"

Dr. Cheung: Yeah, and what's awful is that in the COVID context, I was wearing my facemask and so I couldn't do the typical thing of like calming people down and smiling and saying like, "Don't be afraid. I'm not scary or I'm not going to touch you", when you're all masked up, you can't do that. But thankfully she was talking to a younger friend or something like that who he, he locked eyes with me, and he was embarrassed for her. And so, in that moment that I was like, oh, that really was for me. Okay, I'm going to go now.

So, I think that if we just create a space where we can laugh at ourselves and, not at each other's expense, we will create a learning environment that increases the empathy that we feel for each other and just makes the time that we have here together just so much more worthwhile and connected. And, yeah, no one should be going through cancer alone.

Edith Aquino: Thank you so much, Dr. Cheung, for talking to us. It's such a big deal for AYA to have a voice nowadays. So, you're the perfect voice that everybody needed to hear. Thank you so much.

Elissa: Yes, thank you.

Dr. Cheung: Thanks so much for having me both of you. It's great to do this.

Elissa: And thank you to everyone for 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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