

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Facing Racial Disparities as a Black Disabled Patient'

Description:

Join us as we speak to Ola Ojewumi, a patient and health advocate with Post-Transplant Lymphoproliferative Disorder (PTLD), a type of Non-Hodgkin Lymphoma. In this episode, Ola tells us about the difficulties she has faced as a Black disabled woman with chronic pain. She shares about her experiences with racism and inequities in healthcare and how she has learned to advocate for herself and others.

Transcript:

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

Edith: I'm Edith.

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

Elissa: Today we will be speaking with Ola Ojewumi, who is a Non-Hodgkin Lymphoma survivor, as well as a heart and kidney transplant recipient. Ola is a writer and a community organizer based in Washington, D.C. She is the Founder of the global education nonprofit organization, Project ASCEND, where she is a champion for higher education in marginalized communities. Ola has also advocated on the national stage for affordable healthcare, health equity, and minority disability rights. Welcome, Ola.

Ola Ojewumi: Thank you so much for having me.

Elissa: So, let's start with your diagnosis. You were diagnosed with Non-Hodgkin Lymphoma of which there are many, many types. What type did you have and what led to your diagnosis?

Ola Ojewumi: I had a form of post-transplant cancer called PTLD, Post-Transplant Lymphoproliferative Disorder. So, what caused my cancer was my organ transplants due to immunosuppressive therapy that I've been on since I had my organ transplants at age 11. So, because my immune system was suppressed, it left my body vulnerable to developing cancer, and that's how I developed lymphoma.

Elissa: Wow! What signs and symptoms were you experiencing leading up to that?

Ola Ojewumi: The symptoms I had were just swelling of the lymph nodes; and that's pretty much it, actually, just swollen lymph nodes.

Elissa: So, you got diagnosed and then what was your treatment like?

Ola Ojewumi: I received a six-week treatment of Rituxan®. Instead of doing chemotherapy, the therapy came in the form of immunotherapy. It was a rough six weeks, but I got through it with very few side effects. I didn't lose my hair, thank God.

Elissa: What was the follow-up treatment or were you completely done after that?

Ola Ojewumi: Basically, my doctors keep an eye on the mass, and we do scans every year to watch the progress.

Elissa: So, you still have a mass in there.

Ola Ojewumi: Yes. But it's shrunken significantly-

Elissa: Good!

Ola Ojewumi: -since treatment.

Elissa: So, do they expect that to completely go away or is that just kind of something that's expected to be there for the rest of your life?

Ola Ojewumi: It's expected to be there for the remainder of my life, but we just watch the growth and see if it's grown or if it's shrunken in size. If it needs to be treated again, we'll do another round of Rituxan®.

Elissa: Now, the location of the mass, is that what led to you being in a wheelchair?

Ola Ojewumi: No, I actually have a rare muscular disease called Mitochondrial Disease.

Elissa: Oh!

Ola Ojewumi: So Mitochondrial Disease can cause organ failure, hence, my organ transplants. So, it's a genetic disorder.

Elissa: When did you go into the wheelchair? Was that after your lymphoma diagnosis or before?

Ola Ojewumi: It was after my lymphoma diagnosis. I'm a part-time wheelchair user, so I can still walk a little bit, but the wheelchair is for distance.

Lizette: And have you experienced additional hardships or even discrimination in the healthcare system as a result of being in a wheelchair?

Ola Ojewumi: I've mostly experienced discrimination when it comes to pain management. Dealing with trying to show doctors that you're in pain. As an African American woman, you deal with medical racism and part of that comes with pain management. And, statistically, people of color are given less pain medication than white patients and are less likely to believe. I mean, there was a recent study showing that medical students believe that black patients could endure more pain than white patients.

Lizette: Oh!

Ola Ojewumi: Yeah.

Lizette: Wow!

Elissa: Yeah, that's not helpful.

Ola Ojewumi: Yeah, it's not.

Elissa: Have you had any other issues related to your disability and healthcare?

Ola Ojewumi: I've had my battles with doctors and, getting them to understand where I'm coming from, getting them to understand that my chronic pain is real and valid; and getting proper treatment has been difficult. But I've overcome a lot of challenges; and overcoming different battles in the healthcare system haven't been easy, but they've been totally worth it. I've come out scarred, but I've come out strong.

Edith: There you go.

Lizette: Definitely.

Elissa: Now I saw on your Instagram when you were in the hospital, I believe over the summer, and there was a situation with not being able to get oxygen when you had asked for it. Could you tell us about that?

Ola Ojewumi: Yeah, when I was in the hospital, I felt like I was having shortness of breath, and I filmed my journey within the hospital because some of the things I personally cannot believe happened to me in the hospital. Like not being able to get oxygen that was a big deal for me, so I turned on my camera and recorded it and shared it with my followers just to show that people of color and people with disabilities are often mistreated in the hospital. And it felt like I had COVID, but I didn't. I eventually tested positive for COVID months later, but I'm fully recovered now and feeling great.

Lizette: Good. I think one of the things that you're bringing up is really important, Ola, just because you know how to advocate for yourself. You're able to just say, "I

need this." And there's so many patients out there that don't feel comfortable or don't know that they can tell doctors or tell healthcare professionals what they need. So, I think it's really important what you're doing is helping empower people know that they can ask for what they need, especially if they're not getting what they need in the healthcare system.

Ola Ojewumi: Yes, self-advocacy is important and sharing that story of self-advocacy was important for me because I know a lot of patients are scared. Doctors, hospitals, medical staff, it can be intimidating trying to convey what you need to people and struggling on whether you'll be believed or not and whether your issues will be taken seriously.

Lizette: It's, so sad to think that you're scared to speak because you don't know if somebody will believe you or not and you know your body and you're the one that's feeling what your body is feeling. So, I think that's, for me, one of the hardest things to hear.

Ola Ojewumi: There was a hashtag #PatientsAreNotFaking. It was a popular hashtag on Twitter amongst people with disabilities. There was a video of a nurse actually doing a skit saying, "We know when you're faking." And so that inspired the hashtag #PatientsAreNotFaking. So, it's a disease amongst medical professionals and people in the medical system who do not believe patients, who do not listen. But if you continue to advocate for yourself, you'll force them to listen and take you seriously.

Elissa: Have you experienced that much of your life, people just not believing you?

Ola Ojewumi: Yeah, especially with my transplants. I'll give you an example. When I was 12, I had my transplants in another state. I had my transplants at Children's Hospital of Pittsburgh. So, when we returned to Maryland where me and my family are from, we were trying to convince the doctors that I still had walking issues. And my pediatrician actually said to my mother, "Your daughter had a heart transplant.

She's fine now. She doesn't have walking issues," even though I suffered nerve damage in my right leg as a result of my kidney damage and I was using a walker; and trying to figure out why I was still struggling walking and convincing the doctors that, hey, everything's not okay. The heart transplant didn't repair everything.

Elissa: What do you think that we could do as a country, as a nation, to help improve that and help improve racial biases and just general not believing of the patients in healthcare?

Ola Ojewumi: Patient advocacy is key. I think every medical student should have to go through a class where they actually are featured with patients telling their stories about issues in which they weren't believed, and they weren't listened to. So patient advocacy is key. I feel like it should be learned within medical schools' courses and curriculums that are rooted beyond just textbooks, but actual patient experiences are taken seriously. So, incorporating that into the classroom would be really great for this issue.

Elissa: That's a really good idea. Have you pushed for that in your own advocacy work?

Ola Ojewumi: Yes, I have. I've been on several healthcare panels talking to doctors, talking to patients, giving speeches. I've even spoken alongside Nancy Pelosi.

Elissa: Wow!

Ola Ojewumi: One of my speeches went viral, and it was a speech alongside Senator Cory Booker and Senator Bob Menendez. It was about the ACA. It went viral with 3.7 million views on Facebook talking about my experiences within the healthcare system.

Elissa: We'll go ahead and find that video and put that into the Show Notes for our listeners.

Edith: So, the current COVID-19 pandemic has also shown more difficulties for those in need of medical care, in particular our underserved and racial minority communities. Aside from you getting COVID-19, how has the pandemic been for you?

Ola Ojewumi: It's been really difficult. I haven't been able to see my doctors regularly because we're all on lockdown. Thank God for telehealth, but it's been difficult just being able to do community organizing and having to switch to a virtual environment. I'm used to speaking on stage and now it's speaking through Zoom. My advocacy has slowed down a little bit because everyone's focused on the pandemic. People with disabilities are missing out on things like home care, therapy. It's a lot. It's a lot to miss out on.

Elissa: Has it been difficult being in a wheelchair and being able to get around and other potential difficulties with public transportation?

Ola Ojewumi: People with disabilities have a difficult time getting around before the pandemic and now it's even worse because there's limited options with paratransit. Uber actually does have a wheelchair. In D.C. we have Uber WAV, Uber Wheelchair Accessible Vans.

Elissa: Oh great.

Ola Ojewumi: Yeah. But it's still difficult to get around because some of the busing systems and public transportation systems are closing. D.C. wanted to close the metro system on weekends. That would hinder people with disabilities ability to get around and get to the hospital if need be. So, having public transportation change for the worse has really affected the disabled community during the pandemic.

Lizette: Sure, as well as the disabled community that doesn't live in a major city, that may be in a rural area where there's even less chance for transportation.

Ola Ojewumi: Yeah. I'll just be honest, I don't know how people with disabilities survive in rural America 'cause the nearest hospital is two hours or three hours away

as opposed to in a major city where it's 10, 15, 20 minutes away. It's very difficult being a person with a disability in a society that's built for able-bodied people. And public transportation and modern transportation still hasn't kept up with the times and the demand and the needs of people with disabilities.

Lizette: True.

Elissa: So, you have now become an advocate not only for health equity, but also for racial minorities with disabilities. How did you get into all of that?

Ola Ojewumi: Yeah, it was all by using my voice and speaking out and working with organizations like Planned Parenthood Metro Washington. I was a part of their Developing Leaders Program. And I got my start with public speaking with elected officials based on an email they sent saying they were looking for stories about people who were impacted by the Affordable Care Act. So, I gave a speech about how the Affordable Care Act impacted me and my cancer diagnosis because when I was diagnosed with cancer and treated, I was able to stay on my parents' health insurance. And I told that story on stage with a few politicians, and it transformed into being invited to speak on panels, being invited to speak at schools, being invited to just share my voice.

I started my nonprofit when I was in college, and it's enabled me to award scholarships, college scholarships to people with disabilities because I feel like education is the great equalizer. Only 19% of students in college have disabilities. That's a low number. In order for us to be able to be able to be advocates, to be able to be self-advocates, to be seen as equals in this society is partially through education.

And so it started with a \$500 refund check. I got a refund check for a scholarship that I won, and I used the money to start my foundation. And thus far, we've distributed over \$30,000 in aid for college scholarships and grants.

Elissa: Wow, that's amazing.

Lizette: Congratulations!

Ola Ojewumi: Thank you. It started with a dream of just wanting to impact my community and wanting to see more people like me on college campuses.

Lizette: It always starts with a dream, right?

Ola Ojewumi: Yes.

Edith: Breaking that glass ceiling. You go, Ola.

Lizette: Ola, you've been able to be a self-advocate, and I just want to hear some of the tips that you can give to patients and even caregivers, people, their loved ones looking over them where they can become self-advocates or advocates for their loved ones. Sometimes it's not so easy.

Ola Ojewumi: It's not easy at all. I recommend always taking someone else with you to go to your doctor's appointments, so you don't second guess yourself. If they see something that's wrong or if they hear something. If they can see that you're being mistreated, they can step in as an ally and speak for you if you don't have the strength to speak for yourself. And preparing questions ahead of time. When you talk to your doctors and researching your condition, you know your body the best, better than any medical book any degree that anyone has can tell you. So, doing your research ahead of time and showing the doctors that you know what you're talking about and that you know your body and your condition just as well as they do, if not more.

And don't be afraid to question authority. Or to be frank, make a scene. I don't think there's anything wrong with showing human emotion and showing anger or showing that this is upsetting you because your life is in the balance.

Lizette: I think if you don't speak up, also, people don't know what you're thinking. your treatment team is not going to know what you're thinking, where your mind is,

how you're feeling. Most of us go into a doctor's office the first thing the doctor says is, "How are you feeling?" And you say, "Fine." You know, it's just, I think, typical of us to just say "Fine" but not really open up and say what's really happening. And I think particularly with a cancer diagnosis, you have to be very frank, very honest.

And another thing is exactly what you're saying. If you don't feel your healthcare team is listening to you, then you can also get a second opinion. We shop around for cars to get the best deal, but a lot of us don't think that we can look for another treatment team that we might be able to communicate with better.

Ola Ojewumi: That's factual. There's more than one specialist for every disease. And shopping around for a good doctor, a good doctor is hard to find. It really is. So, don't feel like you have to take a first opinion and that only. Always get a second opinion if you can.

Elissa: Yes. And you want to have a care team that listens and is doing the right thing for you. And something that Lizette brought up was that a lot of people, again, don't say how they're feeling. They don't tell the doctor the truth, and they don't keep track of things. And at LLS, we have a *Health Manager App* where you can write down, any issues, any symptoms, signs that you've had in between doctors' visits so you can have that available to you when you come in to be able to show the doctor. And we're hoping that that has been helping some people 'cause I know I go into my doctor and I don't remember, you know, some things. And I leave and I'm like, "Dang it, I should've said that." And so, its, I think, part of that importance of the self-advocacy and to make sure that you are giving the information to the doctor because they need that as well, but they should be listening to you, so you definitely want a doctor that's going to listen.

Ola Ojewumi: Some doctors will allow you to record the doctor's appointment, and that's not a bad thing to ask just so you make sure that you can remember everything that was said. Especially with treatment, sometimes you're so foggy and you're so

sick, you can't remember what you just said or what he just said or what she just said. So, I love the idea of the app. I might download it.

Elissa: Yeah, you should.

Lizette: Yeah, definitely. And what you said too about bringing somebody else just because you may be in an appointment and you may think that the physician might not have heard you, but your caregiver or whoever has come with you to your appointment might see it a different way or vice versa. So that's also something good about having somebody else there.

In the time of COVID, sometimes that has been very difficult, so I agree with you if you can ask the doctor, and many, like you said, are happy for you to tape the conversation or write things down; but I think it's very important what you're saying.

Ola Ojewumi: Thank you. I don't mean to incite anything. I just feel like it's, it's okay to express yourself and be emotional at these doctors' appointments because you're dealing with something heavy like cancer. That's something that changes your whole life and changes your whole perspective. And staying reserved and quiet and meek, it's not good. Express yourself in whatever way you can because it could end up saving your life.

Lizette: Yeah, and there are many doctors out there that are great doctors and we've been able to work with a lot of them that have really been open and have really engaged patients in coming up with their next steps for treatment the way that it should be. It's really important to make sure that you know that you're part of your treatment team. We always say, "Your treatment team," but you're pretty much the most important part of your treatment team.

Ola Ojewumi: Indeed.

Elissa: One thing I wanted to kind of go back on and touch on was you had talked about, videotaping your appointment when you felt like, you weren't getting what you

needed. And we've seen that in other instances. For instance, that First Nation woman in Canada that, ended up dying because she was getting discriminated against in the hospital. You have the doctor dying of COVID who videotaped herself and hearing things that the staff was saying. How do you feel about all that with videotaping and dealing with this racial discrimination in the hospital?

Ola Ojewumi: I feel like the camera is our greatest weapon to hold people accountable. You can file a complaint against a doctor, and it can go nowhere; but when you record the situation in real time and you allow others to see what you're seeing and see what you're experiencing, you're liberating oppressed people by doing so.

COVID-19, we're living in a scary time, and it's sad to think that your race could be a determining factor in whether you live or die and whether you're believed or not and whether you receive oxygen or not, whether your symptoms are taken seriously. So, the cell phone camera has shown itself to be proving what people of color have been saying for years and are still not believed even though they're on their death beds showing you that this is disparate treatment, that they're being treated differently than white patients.

So, all I can say is liberate yourself and record everything, because once people feel like they're being watched, they feel like they have to do the right thing or else they'll end up the next viral video. But also filing complaints after the fact are good too. I want to emphasize that the only way we can kind of get rid of racial biases is to hold racist doctors and racist medical professionals accountable.

I actually did this with my pain management specialist. I wrote a review on Yelp complaining about the way in which I was treated by a pain management specialist. And the pain management clinic ended up hiring a black doctor and hiring more African American staff after I wrote that Yelp review.

And in the Yelp review, I included the studies that show that with pain analysis, African American patients are less likely to receive pain medication. I included that, and I made sure that I made my voice heard by leaving a review and complaining. There's nothing wrong with filing a complaint. It's needed. It's necessary because you could be saving a life.

Elissa: It's that feedback that I think that people in every profession need but particularly medical professions that they need that feedback if, something is not going right or if they could do better. And if they don't get it, then how will people ever know if they can do better in their own profession? I think all of us can say that we want to succeed, and we want to do well in our profession and treat people well and do our best. And if we're not given that feedback, even if it's negative, then we can't do that; we can't learn and we can't grow, and I think as a country we can't grow unless we know that this stuff is going on.

Lizette: And I think what's important is that you showed that you weren't the only one. You weren't just writing a review to complain. You were writing a review and you were proving that this isn't just happening to you, but it's happening to so many people.

Ola Ojewumi: Yes. We all have to be advocates for each other as well as patient advocates.

Edith: On our patient podcast home page we have a quote that says, "After a diagnosis comes hope." Based on your cancer journey and advocacy experience, what word would you choose to complete the sentence. "After diagnosis comes?"

Ola Ojewumi: After diagnosis comes hardship, but through the journey of hardship, you gain strength.

Elissa: I love that.

Lizette: Very nice.



Elissa: Thank you so much, Ola, for joining us today and sharing your incredible experience with us and our listeners. We so appreciate you. And we're really looking forward to seeing more of you on the national stage as we continue to fight for health equity and then access to affordable and quality care, so thank you.

Ola Ojewumi: Thank you so much.

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

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](https://lls.org/PatientSupport). You can also find information specific to young adults at [LLS.org/YoungAdults](https://lls.org/YoungAdults). All of these links will be found in the show notes.

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.