

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Moving Forward with Myeloma: Oya's Story'

Description:

Oya knew he was sick, but his inclinations were met with people telling him he was a hypochondriac. Oya recounts the moment in his life when he decided to increase his health insurance after being told by doctors that he was fine for many years prior. It was during the insurance company's own testing that they told him something was wrong and instructed him to bring their results of his blood work back to his primary doctor. Through a series of tests, he later received his myeloma diagnosis. Listen in as Alicia, Edith and Lizette speak with Oya about the importance of advocating for yourself when something feels 'off'. Having been diagnosed in his 40s, Oya shares how he was diagnosed, signs and symptoms he experienced, the effects of his treatment, the importance of open communication with a patient's healthcare team and the vital role of a caregiver. He describes the many friendships he has made throughout this journey and the lessons he has learned about life overall.

Transcript:

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

Edith: I'm Edith.

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

Alicia: Today we will be speaking with myeloma survivor Oya Gilbert. Oya is a father of three, a daughter and two sons.

Oya has been in management for over 15 years, working in NFL stadiums and automotive manufacturing plants. Fun fact about Oya, he released a hip-hop record in 1990 as writing and music production is a passionate hobby of his. Glad to have you on today, Oya.

Oya Gilbert: I am glad to be here. How's everybody?

Lizette: Welcome. I think we need to have a little bit of that record for us to play for our listeners.

Oya Gilbert: Oh, I knew it was coming.

Alicia: What was the record?

Oya Gilbert: Well, when I was younger, because I'm a lot older now, I was definitely heavily involved in hip hop late '80s, early '90s. Actually, spent some time living in New York, and I produced a record at the time which was called *Project X*. You can google it as well. And that's what I really wanted to do when I was younger. Life circumstances took me in a different direction; but the record was pretty popular in the tri-state area which is considered Delaware, Philadelphia, and the southern portion of New Jersey.

And it did really well and got a couple little videos out there. But, yeah, it's definitely been a passionate hobby of mine. Since I was 14, I've been writing and just love music. A couple of my uncles play instruments.

I never could get with the live instruments. I never really was good at it. I was a, kind of a computer geek. Basically, I was a nerd. And so when hip hop came out and everything became kind of electronic, it was the perfect blend for my 'nerdism' and music loving at the same time. And that's what it manifested into, which I still continue to do today as a therapeutic thing for me. Music is very relaxing for me. Some people play golf, and I make music.

Alicia: Awesome, we each have our thing, right?

Oya Gilbert: Yes. Yes, we do. Yes, we do.

Lizette: Well, I have to look that up. That's my genre, so, I'm going to look that up.

Oya Gilbert: You do that. You definitely do that. It's going to be old school. You've got to remember it was the '90s.

Lizette: I am old school, come on.

Oya Gilbert: All right, not like today's music, but it's certainly-

Edith: Oh, you don't do mumble rap? Come on.

Oya Gilbert: No, no. No mumble rap. Oh, actually, something really cool that happened to me. A couple weekends ago, they surprised me, invited me to Delaware; and I received the Delaware Lifetime Achievement Award in hip hop for my contribution to hip hop, which was a really awesome event. I was completely humbled

and taken back by the event and the outpour that came on Facebook and the people that showed up that I hadn't seen in years. So it was a surreal moment for me.

Lizette: Wow.

Alicia: Wow.

Oya Gilbert: Yeah, yeah, so.

Alicia: That's a great accomplishment. Congratulations.

Oya Gilbert: And I got multiple myeloma.

Alicia: Well perfect segue. And to the topic for today's episode, we are going to be talking about your journey being diagnosed with myeloma. And for our listeners, myeloma is a cancer of plasma cells. In myeloma, a plasma cell undergoes a malignant change caused by one or more prior genetic mutations. In the early stages of myeloma, some patients have no signs or symptoms. Other times myeloma is determined as a result of laboratory tests done to show abnormalities in the blood and/or urine, or the most common symptom is bone pain and fatigue. In most patients with myeloma the disease already involves multiple sites at the time of diagnosis and because of this the term multiple myeloma is sometimes used to refer to the disease in its most common form.

So, Oya, how were you diagnosed?

Oya Gilbert: My story begins two years before 2017. My whole life, I really haven't been a person who's had any major illness. You know, colds here and there. The irony of it, I've never broken a bone, even though I have a bone marrow cancer. That's the funny part about it. And all of a sudden, I started having different issues.

One of the major issues was just this extreme fatigue that I was having, and I tried to do all the things that most Americans probably know. You eat some sugar, you drive and roll the window down, cold water on your face. It was way beyond that. And those "episodes," as I called them, were happening once in a blue moon, maybe once every two months.

And then I started having issues with shortness of breath. I could, at some point could run two blocks up the street to the local store; and then other moments I couldn't even walk into the kitchen. And then just a lot of different pains.

So immediately I started going to the doctors, I went to a neurologist. He did some blood work. Nothing came back. And eventually I wound up seeing every kind of “ologist” you could possibly think of – a mixologist, a zoologist, a cosmetologist.

And, you know the bittersweet thing of it was at some point they told me what I didn’t have. So that was comforting. But then in the same breath I knew I was sick.

So that went on for a couple of years, and then eventually it was happening every day, all day while I tried to live a normal life with my two boys and trying to raise them. And at some point I really just believed I was going to fall out and die, and it was going to be one of those kind of stories where you don’t show up to work for a few days, and people wonder where you’re at, and come kick in the door, and there I was.

So I decided to increase my insurance policy and I called the insurance company up and said, “Hey, I need to increase it, blah, blah, blah.” So they sent their doctors out to me, and they ran some tests. And, obviously, they denied me because they said, “You’ve got some issues going on. It could be your kidneys or whatever the case may be. So take this information to your primary,” and I went through a few primaries because at some point they were considering me a hypochondriac. You know, they just thought I was making stuff up and said it was anxiety. And I said, “Dude, this is not anxiety.”

So I took that paperwork to my primary, and would you believe it was almost like instantly, I went from a urine test to hematologists to oncologists. I met the oncologist. He sent me to get a bone marrow biopsy. And on December 26, the day after Christmas in 2017, I was told that I had multiple myeloma, which is an interesting story in itself, if you remember Charlie Brown and the schoolteacher and she talked like, “Whomp, whomp, whomp, whomp.”

Alicia: Uh-huh.

Lizette: Yep.

Oya Gilbert: Yeah, it wasn’t what I envisioned being told cancer was. I thought it was going to be like you sit down, brace yourself. He came in and said, “Hey, how you doing, Mr. Gilbert? Hey, remember that nasty cancer I was telling you about? Yeah, you got it.” And from that point on-

Alicia: Oh, wow.

Oya Gilbert: -it was kind of the “Whomp, whomp, whomp.” And I just started thinking about my kids, and I was like did this guy just say I had cancer? And did he just say it was incurable? You know, and I’d never been sick. And I left the doctor’s office without asking him any questions. I was just dumbfounded; and I sat in the parking lot, cried a little bit, thought about life, and then realized, hey, dude, you never asked him which stage you were in or what you were going to do. So, thank goodness, he gave me his business card and I called him

Alicia: Wow.

Lizette: I mean you really had a long rolling out period.

Oya Gilbert: Yeah.

Lizette: Years, wow.

Oya Gilbert: Yeah, years went by and, like I said, you would think they, they took my blood at that point when I was coming in saying, “I’ve got this issue or that issue.” They were drawing blood all the time. But from my understanding, you’ve got to be looking for something specific. There’s no, there’s no all-purpose blood test that just tests for everything.

So it was frustrating, but in the same breath, it was very relieving. Even though it was cancer, it was very relieving to know what it was, so to see what we could do about it. And the beautiful thing about divine intervention is for all those years that they couldn’t figure it out, when they finally told me everything, I was only in stage 1, which was great. There was a lot of positives, that’s what I’m saying. I was in stage 1, and normally what happens, from my understanding, now that I’ve been living with this disease for a while, is normally, you know, it happens in elderly or older folks. So they were very surprised that I even discovered it.

As you said in the lead in, it sometimes goes undetected. And normally what happens is it attacks the small bones, and so something like, you might sneeze or cough really hard, and you’ll crack a rib or something of that nature. Or do something very simple with your fingers and break a finger. But, obviously, if you crack a rib, you’re going to doctors and they ask you how, what happened. And you’ll say, “I wasn’t doing anything, and I did cough.” It’s kind of like a trigger for them to start digging in that direction.

So I didn’t have any of that. Like I said, I was in stage 1. I wasn’t in the point where normally around stage 2. It only has three stages. Normally around Stage 2.5 or 3,

you're at that molecular level where it's eroding your bones. So that was a blessing, and then, and I'm sure we might get into that later.

The treatment plan that they prescribed for me, you know, I responded to the very first medication they gave me, which could also be very frustrating as a, as a cancer patient trying to get an answer and get treatment, going through different medications, trying to find the right one. So all that stuff was a blessing, even though it was a dark situation.

Alicia: Oya, you mentioned earlier that people were saying, "You're just a hypochondriac. It's fine. You're fine. You know, just kind of settle down." They always tell people that they have to be their own advocates because-

Oya Gilbert: Absolutely.

Alicia: -in a doctor's office, there's two experts. There's the doctor who's gone to school for what they're telling you, and then there's you who knows exactly how they feel. So how important for, was it for you to stress the point that you weren't just being overly anxious, but this was actually something that you wanted them to pursue and look into further?

Oya Gilbert: I agree with your comment whole-heartedly because you do have to be your own advocate. For me it was extremely frustrating in the beginning because not only are you dealing with people that, I'm not saying that they're not listening. But they're not, not listening. You know, they're not believing what you're saying.

Alicia: Right.

Oya Gilbert: And then it's compounded with you are still dealing with these symptoms, and they're getting worse. So you're sick, and you're trying to convince people that you're sick and they don't really see it the same way. So it was extremely frustrating. It was very important for me to be my own advocate because nobody knows my body better than me.

Alicia: Right.

Oya Gilbert: And the things that, as explained earlier, you know, I've never really been sick. So this was very easy for me to see. You know, maybe not the doctors because they, they just see paperwork and a history. But I've never been really sick or had any major diseases.

So I just kept pushing, and I went through a couple primary doctors. I had some very uncomfortable conversations with some doctors, and I can be very direct when I need to be. And I switched doctors to finally Dr. Owens, which is my primary doctor. He actually believed me; and he said, "Hey, let's just revisit this from the beginning." And he just actually listened, he was hearing me and listening. The other people were just hearing me.

Alicia: Um-hmm.

Oya Gilbert: And, so he started doing some things and asking me to try some stuff and go to this place. But he kind of started the whole process of, over going to the cardiologist and so forth and so on. And so, like I said, between that and making me feel more comfortable, because at some point I started believing them that it was anxiety; and they had me on all these pills, and I'm not a big pill person, like taking pills. I can take them, but I just don't like to be dependent on something to survive, which is ironic now.

But that's kind of how that went, and so I just suggest to anyone who has any kind of situation, you do have to be your own advocate. Because a doctor is very intelligent. But the reason why they ask you what symptoms are is because it's a guessing game for them as well. So they ask you for your symptoms so they can kind of narrow it down.

Alicia: Yeah.

Oya Gilbert: And my symptoms were all over the place, so they just kind of, I guess, some of them just chalked it up as I was a hypochondriac, which I was not. I was right. As a matter of fact, I wanted to catch up with that first primary doctor – I know it sounds crazy – and say, "See, I told you. I had cancer."

It's very important for you to know your own body and do something about it because there's some folks that may be experiencing some things and just kind of brushing it off, and I'm a male and I know how the ego works sometimes with us guys. It's just reality. And we'll put things off till it's like out of control, go to the doctor because you think something's wrong and let them tell you that there's nothing wrong. Just don't go see my doctors.

Alicia: Right, and you bring up a good point because there's gender that plays a role, there's upbringing that plays a role, there's, generational differences when those who are told the doctor knows best. So you kind of listen, take notes, and do exactly what

they say. But we always stress the point that it's so important to feel comfortable with a person's healthcare team; and that's why we stress the importance of the, of the value of a second opinion. And if someone isn't comfortable with somebody knowing that they have the complete right to go somewhere else and get the answers to the questions they may have or at least get the comfort that they feel like we should have, especially at such a challenging time.

Oya Gilbert: Exactly. I mean I understand why some older generations keep that same doctor for years and years and years, because they're comfortable with them. And then you create a history that's not just on paper. It's a relationship.

Alicia: Right.

Oya Gilbert: And so I think that's, that's critical like you said. So it's, definitely be an advocate of your own health. An advocate of anything, but definitely your own health.

Lizette: Right, and the ruling out process is a little different with you because, as you said, they are not thinking. You know, they're trying to rule out everything that's more common, right? But at the same time, if you were more advanced in your age, they might have picked up on it more. Because we are finding more and more younger patients diagnosed with myeloma. But, you're right, most of our patients are still more advanced in age.

Oya Gilbert: I love the way you put that. I'm going to have to steal that from you. Advanced in age, that's a really nice way of saying it. Yeah. You're exactly right. I'm not advanced and aged. So, yeah, it was something different.

What I didn't know and what I did learn was that multiple myeloma was common in African Americans, which I happen to be, in case you couldn't tell from the voice. That was kind of one of those wow moments; and I was like, "Really?" And he's like, "Yeah." It was a different situation for me going from the diagnosis and then going into the treatment and just everything that I had to process in a very short period of time because the doctor, after he explained everything about the different treatments and then also the stem cell process, it was a lot of information to take in, in a short period of time because he explained to me, "Hey, take your time, but don't take your time." That's exactly how he said it, and I understood what that meant.

So I made a decision very quickly, and going from the day after Christmas in 2017, I started treatment February 1st of 2018 in preparation for getting the myeloma under control hopefully to then have a stem cell transplant.

Lizette: And that's an autologous transplant from your own cells.

Oya Gilbert: Yes, I did get my own cells. I still had the ability to get my own cells, which I chose that. And they, you know, with anything, you have all those percentages that they spew out at you. Obviously, anything of your own gives you the greater chance of success. So, yeah, I did get my own stem cells; and that process was rather interesting. I don't know if you want to talk about it now or later, but it was definitely a rather interesting process going through that whole extraction of the cells and then the chemo and so forth and so on.

Alicia: Oya before we jump into that, you were saying that you didn't know certain things about the disease. For example, that it affected more African Americans. And for our listeners that also don't know, African Americans have twice the incidence of myeloma as white Americans. And what's more is that recent studies show that African Americans are significantly less likely to receive the latest treatments and more likely to experience treatment delays for a number of reasons, which is why LLS actually created a resource called Myeloma Links, which connects African American communities to information, expert care, and support.

Now what other questions did you have during this time, because I could only imagine this is the disease that you felt something was wrong, people are telling you that you were a hypochondriac. Then you actually get the diagnosis, and now you're kind of finding out what exactly is this. You hear what the doctors are telling you, but where did you go with the questions that you had outside of the doctor's office?

Oya Gilbert: I did some research online. And I, I say that with hesitation because, you know, when you go online sometimes, you know, if your fingernail gets cut, if you dig deep enough, it could lead to death. You know, so.

So I didn't really have a lot of knowledge of what was the proper, you know, outlet or resource to look at online. So I went on WebMD, those type of resources to get what I would think is credible information. And then I jumped onto a couple of, just typing in multiple myeloma blogs and things like that. So I did a lot more of trying to find people who actually had it as more so than looking at information from medical professionals online. I did do both, but I kind of wanted to get a gauge of what was I dealing with, and I thought the best people to talk to was people who actually had the disease.

So I kind of went a different route. I certainly trusted what the doctors were saying once we figured out what it was. But outside of the office, I did more research of

looking on blogs and typing in and chiming in and befriending some of the folks and speaking with them about their experiences. Obviously, the biggest curiosity for me was always “when was you diagnosed and where are you at now” to see the lifespan. You know, that’s a, that’s a real thing. You can’t avoid that. And so that’s where I did a lot of my extra research online was blogs with current patients or caregivers for that matter.

Alicia: Absolutely.

Lizette: And did you find enough support systems?

Oya Gilbert: Yeah, I actually did. And I love information, so I, dug deep and jumped on as many blogs as I could. And then I took that information and then compared it with the WebMD or whatever publication that was on and compared the information, if you understand what I mean, and then compared that with what the doctors were saying to draw my own strong conclusion of feeling comfortable about where I was going with this or where we were going with this, with the treatment or, or what the disease could do in general.

So that was extremely helpful, so that was the route I chose. Everybody might not choose that route, but that was the, a way that helped me outside of the office and just taking that information because you don’t go to the doctors every single day.

Alicia: Right.

Oya Gilbert: So you got appointments and in between that time it’s all this dead time. As my grandma used to say, “An idle mind is the devil’s workshop.” So, I really wanted to understand what was going on because it was, once again, I’ve never been sick. So everything about this was new – cancer, all this stuff.

And, I’ve had family members that have passed from cancer and close friends and coworkers and things like that. But it’s a lot different when they say, tell you you have cancer. I’ve never treated hearing about cancer lightly, but, obviously, when somebody tells you, you have cancer, it changes your whole mindset on how you’re going to look into the situation.

Lizette: So it’s interesting what you’re saying, that you wanted to hear from other patients. And we hear that from patients all the time and even caregivers. They want to hear information from people who’ve been through it, and that’s really valuable for people.

We have a Patti Robinson Kaufman First Connection program, and that's pretty much a peer-to-peer program. It matches patients and caregivers to people who are newly diagnosed. So you can talk to someone that has been through it or has been through something similar because we understand that everybody's journey is different. We're not saying it's not.

Oya Gilbert: True.

Lizette: But we're just saying that it really is important to speak to somebody else that has it because they're going to understand certain things. And they're going to give you those little nuances that maybe a doctor or a nurse or a social worker can't provide to you, like bring a blanket to chemotherapy because you might get cold. Little things like that, so I think that's very, I think that's very good that you sought out, you know, other people. Did it make you feel a little bit better or not alone?

Oya Gilbert: I wouldn't say not alone. I think we as human beings gravitate towards things that are relatable. And that's what I would say. It was a comfort level that I got sharing a topic with someone that could relate to it. Even your doctors. They're not doctors that are treating you that actually have cancer. Some, some of them have had cancer; but they don't have what you have.

So even though they understand the disease, they understand it from a standpoint of the medical side of treating it, but, you know, when you want somebody to relate to your situation, you want somebody that's been through it. Like I, I've never been married, so it's difficult for me to give my married friends marital advice because I get it, but I really don't understand it. So it's the same thing I felt when I went to the blogs as far as multiple myeloma. I wanted to talk to people that actually have that particular disease and so I could relate to what they were going through and hopefully they can relate to what I had to, my two cents I had to put in.

Lizette: Did it also help you any with your decision-making when it came to the types of treatments that you decided to have?

Oya Gilbert: To some degree because it seemed like there wasn't a whole lot of options. The treatment that I was told seemed pretty across the board with everybody. So it was pretty calming.

And so that made me feel that ease. So it wasn't really difficult. It was more understanding, like you said, the nuances of the side effects and things of that nature. Gaining that information on what I was going to have to go through, because I had

already made the decision on what I wanted to do because, you know, I loved live, and I want to live. So let's do whatever we need to do to get that done.

I just didn't have to take necessarily an extremely high-risk treatment plan because of my stage and all those other good things that were in my favor.

Alicia: And the goal of treatment for myeloma patients is to reduce symptoms, slow disease progression, provide for long remissions, and lengthen survival while preserving quality of life. And the goal of research for myeloma treatment is, of course, developing curative therapies and improving quality of life during treatment.

And you mentioned that you're a lover of life. When you were going through the different options, you mentioned that there wasn't that much variety in regards to what your treatment plan would be. But how was treatment for you? I know that when we spoke prior to this podcast recording, you spoke about stem cell transplant and how no one really prepares you for how that's actually going to go. So for the person listening, what advice or what information can you share with them about your own experience?

Oya Gilbert: Well, the initial treatment is, I was, I want to make sure I get the acronym correct. I think the acronym is VRD, which was Valcade®, Dex and, oh geez, I just lost my train of thought.

Alicia: Dexamethasone.

Oya Gilbert: Yeah, Yup, that fancy word you just said and that I can't. The Velcade® was, was a shot that went in your abdomen, the fat of your abdomen. That's where they try to put it at. And so that was all new to me. They rotate every session. They rotate sides so that, one of the side effects, it can cause bruising and things of that nature. So they try to rotate the sides so they don't get irritated.

I got that once a week, the dex I took once a week as well, but it was 10 pills. But the side effect from that is really their steroid, and it's really, uh, sends you into like an insomnia state after you take it. You know, you just can't seem to get any sleep. So that was something I wasn't prepared for. I dreaded, I dreaded that, the, that one-week thing. Not necessarily the shots. They, yeah, they burned a little bit going in; but it was that next day the area was sore and then, of course, I didn't get a lot of rest from taking the dex. And then the Revlimid®, which is the other, the R in that acronym, That's the actual chemo pill.

So the whole goal is to try to get the myeloma under control to a level where you can even receive the stem cell transplant. So that's the initial thing, to get it under control.

The stem cell transplant is something extra. I had a choice, and everybody does. You don't have to have a stem cell transplant. Some people choose to just do the light chemo treatment that I just mentioned. And my reasoning was my age, that played a huge factor in it. As we talked about the, I forgot already how eloquently you said it. The advanced in age folks might have a different mindset when you're 70, you know, late 60s, 70. You're in a different mindset, and the risks might increase for you taking the aggressive chemo to get the stem cell transplant and the whole process.

So all that information was explained to me, and I researched it in, as well. So it initially started with that. And I believe, if I've got my timeline correct, I think that was three months of doing it that way or four months maybe because it was a six-month treatment plan to get to the stem cell.

And so I did that at first, and that created all kinds of issues initially. But approximately maybe about a month into doing that, I started feeling better. And that's when I realized not only, it's not like I didn't believe them.

But it's, once again, I'm a firm believer on show me, like from Missouri, the Show Me State. Once I started feeling better, I knew that we were on the right track. And it was such, I don't even know if I have the word to describe. It's difficult to express how a person feels when they're suffering from something for a long time and they start to get relief from it. It is a tremendous stress level mentally, physically, and everything.

So I started feeling better, and up until the point of the transplant I felt almost like myself. So I say that to say someone advanced in age might stick with just doing that, which I could have as well. But when I spoke to the stem cell transplant doctor, he said something to piggyback something you said earlier. He said, "There's no cure for this. We're just trying to get you to live long enough for the technology to catch up with the disease." And I understood that very clearly. His analogy that he used to make me understand what myeloma was, was he said, "Consider yourself having a yard with grass in it, and weeds grow in it. And if you don't treat those weeds, they eventually suffocate the good grass." He said, "So the weeds are the myeloma, and your good cells are the grass." He said, "What we're going to do is reduce all of those weeds to a point where we can extract the good cells, and then we're going to give you aggressive chemo so there's nothing but fertilized dirt, good dirt, put the cells back

in you, and hope that we can grow good grass.” But he said, “Like any good grass, like a golf course, you still have to maintain it to keep the weeds from coming.”

And so it was a great analogy. I understood it. I remember it very distinctly. And that is what a myeloma patient is faced with. You’re going to have to get the disease under control, get the weeds under control, kill all the grass and kill everything. Get some new dirt, get some fertile dirt, put your good cells back in or donor’s good cells back in, and then let them grow while you do weed control for the rest of your life or until they come up with a cure. So that’s how my treatment went, and that’s how I made my decisions.

It was very simplistic answers. I’m a very, I like it cut and dry. I don’t want any candy coating when it comes to, especially my life. I told him, “Give it to me straight.” And that made a lot of sense to me. I remember my daughter being in the room when they told, when he told me this story, and he’s telling this grand story about the stem cell transplant. Me and my daughter looked at each other, and I said, “Hey, doc, you ain’t got to run no sales pitch on me. After you said this is going to give me a chance to live longer, sign me up.”

Alicia: Right.

Oya Gilbert: And that’s how it worked for me.

Alicia: Oya, you mentioned something earlier of it being maintenance and how the doctor used that really great analogy to explain what the plan was and what the picture of myeloma treatment looked like. Those who have undergone stem cell transplant may require maintenance therapy. How was it adjusting to this and knowing that the goal is not to cure it at this point in time, but the goal is to make sure that you’re maintaining it and making sure that you continue feeling well and the disease is continuing to be under control?

Oya Gilbert: Yes, so I’ve never reached remission, which is, obviously, the goal for the stem cell transplant and the whole treatment thing. And some people do, some people don’t. However, I have reached a point where it’s what they call unmeasurable. So it’s there, but the test can’t measure it. So, you know, “tomayto, tomahto.” Zero, unmeasurable. That’s all the same for me. I’m happy.

So the numbers went down. The maintenance portion of it was, I would be on a two-year treatment plan at that time frame. And then it would stop, and we would see how things go from there.

The adjustment portion of it for, for me was just trying to live with the fact or learn the new norm for myself. With other certain cancers, they tend to either cut them, cut it out, treat it, and there's no more chemo. But with myeloma, you know, you're still constantly, I call it the slow growing method. You're slow grinding with it, the chemo to keep it at bay. And so you still deal with the effects of chemo, even though it's in a pill. It's still chemo. I get bloodwork every month.

You have to find that happy balance between the milligrams of chemo you can take in comparison to keeping your immune system at a level that's safe. So that's something I didn't know that I had to deal with and learn. I started out at like 15 milligrams of Revlimid®, and we finally found, I worked my way down to 5, which is a good thing. The less you're taking, the less milligrams you're taking means it's not as difficult for the medicine to attack the cancer. So that's a good sign. Plus, that means that's less damage on you from the chemo. So that was, that was a difficult thing that, to deal with.

Some of the small nuances that I notice is you get a paper cut or any kind of cut like that. The old me would heal up, no problem. But now I notice it took a lot longer to heal; and sometimes it, now, it leaves scars. And that's part of dealing with the new norm.

I still sometimes have what I call episodes. You become acutely aware of everything when you go through something traumatic. And so I sit around sometimes and like any little, you know, pain or something like, uh oh, what's that? Uh oh, what's that?

So that can be somewhat part of it. But the fatigue aspect of it still does exist, just not as much. And I do understand the greatest advice they gave was listen to your body. So now I, you know, if I feel fatigue, I take a rest. You know, and, and relax and get myself together.

As far as the stem cell transplant process goes and the after-effects of that, that went pretty smooth. It's really the maintenance portion of taking the medicine every day. That can become a little deflating. I won't say depressing. I would say that could become deflating at times, because you're reminded every day because you look fine. You know, most patients that are doing well with their treatment look fine. You, nobody knows I have cancer unless I tell them. But you're constantly reminded as you take those pills every day that this is what's keeping me alive, and I know for me I've had some moments where, you know, it's not all, it's not all clowns and balloons and bells whistling. Sometimes there is moments where you just feel a little down and deflated, knowing that you have this disease at this moment. It's not curable.

So that was something as far as the treatment afterwards, the new normal I have to deal with. And just simple things. I think I mentioned to you before or offline, I went to the, the dentist one time; and just needed to get some simple dentistry work in. I used to check all those boxes easily, just no, no, no, no, no. But now I was like, "Oh, I've got to check this cancer box and put multiple myeloma." The dentist did some research, and they wouldn't even see me. They were like, "Hey, listen, we need to talk to your oncologist before we do the scraping on your teeth." And I'm like, "Really?"

And so that was new for me and something I didn't expect you know that's not in a textbook I would say or online somewhere. Maybe a blogger might say something of that nature. But I had to see my oncologist, and he had to deem me qualified to get dentistry work; and I was off the medicine for two weeks, so that's how they handled that. You take what I call chemo breaks, so I was off two weeks, got bloodwork right before the dentistry work, and as long as my numbers were good, they went ahead and did what they had to do to do the extraction. So that's just some, you know, quick examples right there of what it's like dealing with the after effect of being on the maintenance. Other people might experience different things. It's the simple things that now all change.

Lizette: I do want to let you know though that our materials do have information about dental work and myeloma because that is a very important topic, and that's something that a lot of myeloma patients feel they need to know. Before they, they start treatment, a lot of myeloma doctors now will say, "Do you have any kind of dental work to do? Because we want you to do it if you have time to, and if it's feasible, we want you to do it prior to treatment. Or you have to, like you said, take a break or a drug vacation before having any kind of treatment. So it's very important that patients know about the dental aspects.

Oya Gilbert: Yeah, I got that same message. Your mouth, as far as that and your gums, when it comes to this cancer and just any kind of chemo treatment, are extremely sensitive where a lot of things can go wrong very quickly if you're not mindful that, you know, you're taking chemo and you need to get that stuff passed through your oncologist.

Alicia: I definitely appreciate you sharing that with us and our listeners because there might be people listening who are experiencing the same thing or might have questions about their dentist appointment coming up so I appreciate you being transparent and sharing those experiences with us.

Oya Gilbert: Oh, no problem. Yes, I enjoy it. It's therapeutic for me as well to speak to the listeners. So I'm enjoying this as well.

Alicia: Was there any point during your treatment journey or conversation with doctors that they spoke about clinical trials with you?

Oya Gilbert: No, actually they didn't. There wasn't any point of clinical trials; and I want to say that it's probably only because of what stage that I was in and me responding to the very first common treatment that they normally give. I certainly think if I didn't respond well to that, that conversation would have come up. So I never, it never dawned on me to talk about, you know, experimental treatments or outside-the-box stuff. So, I didn't ever have that conversation.

The only thing, and this wasn't, the only thing that went wrong, I would say, in this whole experience was the extracting of my stem cells. Now, based on their information, that was supposed to be the easy part, the easiest part of it. It wound up being, I happen to be the 0.1%, go figure. I wish I could win the lottery on that, but I just happen to be the lucky one that had a very bad reaction to it. What happened to me is when you go through the extraction and in order to do a stem cell transplant, they need to collect at least 2 million stem cells. That's the minimum for them to go forward with the process. If they don't collect that, then it's onto a new idea.

They inject you, and I want to say it was called Neupogen®. I hope I'm pronouncing that correctly. They give you these shots to kind of make your stem cells become hyperactive and overproduce. And when you do get that, one of the things that they do explain to you is you could get bone pain from it because, imagine taking a bottle that only holds 12 liters and then you're pouring another 12 liters in it. You know, so it's, it's expanding.

And that's kind of what happens with these shots, only to generate your cells to do the extraction. But then during the extraction, they kind of filter your blood. They hook you up through your port. They start extracting the good cells, leaving the bad stuff behind. And in the process, they have you eating Tums because you're losing calcium.

And for whatever reason, I was eating these Tums like, you know, Tic Tacs. It was, it was just, I was popping 'em. And I started feeling weird, but because everything was so new to me, I thought how was I supposed to know what it felt like to get stem cells extracted from you.

Alicia: Right. Like what's normal?

Oya Gilbert: Like what, what is normal? So for me, I just kept sitting there, but I started feeling more weird and more weird. And one of the weird feelings is, is you can almost feel the, the suction portion of it coming through your body as they extract the blood. And I'm just trying to be as transparent as I can. It, it's a very weird feeling.

But I started getting lightheaded and to a point where it got so severe, I guess my calcium level went extremely low, my potassium level went extremely low, and my reaction to it was almost like I was having a seizure. I couldn't talk anymore. You know, my hands were all clenched up.

In Hershey, the blood, the blood bank is on the children's side of the hospital, so they're standing there looking at me and calling in doctors. I felt like one of those old movies where the patient's down below, and they got that booth up top and everybody's looking at him do this new experiment. But I couldn't tell them or say anything. I'm in my mind saying, "Will you people figure out what's wrong with me?"

So it was a hilarious moment now, not at the time, and it was just a bunch of people, like 20 people wound up being in the room with pens and papers looking at me.

So eventually the emergency room doctors came down and figured out exactly what it was and started shooting calcium and potassium then into my port, directly into my ports and eventually, maybe about ten minutes later, I could start speaking again. But it was a very scary moment in a process that they said it was going to be the easiest portion.

Lizette: Everybody's journey is different, very different.

Oya Gilbert: Yes, ma'am.

Lizette: So now you're calling me ma'am.

Alicia: If a team says this is probably going to be the easiest point and then that ends up being the experience, I can only imagine how it was to say, "Well this does not feel easy," at that moment. But it's great to hear that you got through it and that they're able to figure it out relatively quickly.

Oya Gilbert: Yeah, it was, it was definitely not the easiest part for me, but I'm still here, so that's good.

Alicia: Yeah. How was your support system? Where did you kind of gather that strength from outside of yourself? And the role of caregivers, how did that play into your own experience and journey?

Oya Gilbert: Well, my caregiving experience was very different. Where I live, I have no family around. And my daughter lives maybe about an hour and a half away from me. So, you know, my girlfriend at the time, her name's Kerry, she was it. She was my support system through everything outside of getting introduced to the support group, the stem cell support group that was up there. And then my daughter, you know, coming when she could. But Kerry was there from day 1 to even now. And just the emotional stuff you go through. The caregivers don't have the disease; but they still are going through some of what the disease causes from an emotional standpoint. Maybe not the physical portion of it but the emotional aspect of it, and it's very critical. I certainly wouldn't have been successful without her the way it went down. So it's very important.

And my family, you know, we talked on the phone and things of that nature. My family is about three or four hours away. So it was a little difficult for them to make the journey and be there by my side all the time.

One of the other things is I never understood what was going to happen afterwards as far as caregiving. I really had this impression, and so did my daughter, we had a funny moment sitting at the breakfast table. She asked me was I alright. And I said, "Yeah, I'm feeling good." She said, "No, like are you all right?" in general. And she had this idea that I was going to be, she was going to have to carry me up the steps and give me a bath and all you know. Real deep thing and so did I.

Alicia: Um-hmm.

Oya Gilbert: I thought I was going to be down for the count. But it, it didn't go that way. Actually, like I said, the stem cell thing, it, the easiest thing was the hardest; I wasn't in the hospital very long. I was in there for about 12 to 14 days, which is pretty incredible. And Kerry was there the whole time, getting me things, doing things for me that would have been a challenge.

If it was just as simple as, "Hey, I'm really, really craving something down from the cafeteria," you know, going down there and getting it for me. Sitting in a hotel watching movies with me, trying to keep my spirits up. You know, making sure that, basically, emotionally, I was in good spirits and that's important. You know, I think

your emotional mindset when you're dealing with cancer is just as important as the treatment.

Alicia: Absolutely. And you mentioned something that's extremely important and that being the emotional impact with cancer. Psychosocial care is something that is a term that we're hearing more and more, but it's something that people didn't necessarily think of as the first effect of cancer. And now people are seeing that it has such a great effect on someone's psychosocial space, and it's important to address those things.

So for anybody listening who would like more information or to hear a podcast about psychosocial care as it relates to cancer patients, by filtering our episodes by survivorship, you'll be able to see the listing of those episodes.

Edith: You broke it down, and I'm so thankful for that. And I'm sure anybody who's listening is extremely thankful as well.

Oya Gilbert: Oh, man, I really appreciate that. I'm humbled by that comment. Like I said, I'm just a regular guy with cancer, and I don't know how to explain things. Like you said, I, the technical terms and all that good stuff. And I do know some words, but, you know, a lot of times people just want to hear it plain and simple. And that's kind of who I am, and I appreciate you guys having me on this show because, as I stated before, it's therapeutic to talk about it for me. It's not just for the listeners. This helps me to discuss my story for my own mental state I guess I would say or to relive it and understand how far I've come from one point to another. So I'm super excited and, yeah, now you can join in and not feel like the oddball in the group.

Alicia: You mentioned earlier that music and writing is a huge hobby of yours. We heard from a birdy that there's another resource that you and a friend named Tim Card has created. You want to tell us more about that as well?

Oya Gilbert: Oh, yeah, my good buddy Tim. He just randomly came in my room. I'm like who is this guy? He's not dressed in doctor's clothes or anything. Yeah, our meeting was very weird.

Alicia: He told us about your meeting and how he kind of just wandered in, and you guys just have this budding friendship. And I'm like, "That's so interesting."

Oya Gilbert: Yes, yes. It's probably wouldn't have run across this guy a day in my life if it wasn't for cancer; but I can actually say today he is a very good friend of mine. And in between those caregiving moments where Kerry had to go to work or my

daughter couldn't be there, family, we kept each other company. And he came in the room and played guitar. Like, who does that?

Alicia: I love it.

Oya Gilbert: We had great conversations, so throughout this whole process, where I came out of my situation and him as well, is trying to figure out how to give back. You know, like in some shape, form, or fashion, I'm obviously not a millionaire because I would give him every dollar I could.

So when we were in a support group, we hadn't seen each other in quite some time, it was the first time me and him had seen each other since the hospital, and now we both had hair and all that good stuff. And I remember Tim saying to me, "Hey, that might be Oya."

And so we were sharing the stories, like we're doing now, and the group said, "Hey, man, you two guys should get together and do a podcast or do something. You'll have great chemistry." And kind of did some research online. What does it take to start up a podcast? That's what I googled.

And just coincidentally, now I'm in music, I had everything we needed, so there wasn't anything we needed but our bodies. And so, yes, so we came up with the idea to do the podcast and came up with the name, *Dying Laughing*. We thought that would be really cool. Since we both think we're funny. It was one of the things that helped me through this ordeal.

I did a lot, I watched a lot of comedies in the, in the chemo ward. I love to laugh. It's just something that's helped me through life. I think laughter's the greatest medicine God created.

And so we wanted to put that spin on it and create a show that possibly I would have wanted to listen to when I was in the hospital, to laugh a little bit about it because there are some, you can find humor in anything. You know what I mean? So we just tried to take some funny situations like us meeting, that's funny, and just different things and kind of put a different feel on it. So that's what we did. We came up with the *Dying Laughing* podcast. I've learned a lot about him. He's learned a lot about me. And I've learned a lot about myself doing the podcast with him and how even though we have different types of cancer, it still falls under the blood cancer family. Just share a lot of same things, a lot of experiences, and he's just been a great friend. I'm glad to have met him.

And so those are the things what I'm talking about as far as the listeners, as far as cancer. It doesn't have to always be these dark things. I've created some great relationships out of this from the LLS to the nurses, to support groups. People I would have never met a day in my life are now, are part of the club. And I've had great discussions with them that helped me with my kids and all kinds of different things.

So I know people want to say cancer sucks, but it, some, you know, I truly look at it as a blessing because it changed my perspective on life and how I've moved forward with all different facets of how I do things.

Alicia: And I think it's so beautiful that you were able to form relationships within this and really approach it in a way that wouldn't let this diagnosis and the sad associations be the thing that linger with you guys. I think it's great to hear that you created *Dying Laughing* podcast and that you're able to laugh and joke about this with those around you.

That's serves as the motivation to people who might be going through the same thing and might be in a dark place. I mean you mentioned earlier that not every day is rainbows and flowers, but I mean I think it's important that you don't linger in that space for too long. And your life and your experiences and your story today shows people that you were able to come out of it and you were able to live your life despite having a myeloma diagnosis.

Oya Gilbert: I couldn't have said it better. What a great ending. I couldn't have said it any better.

Alicia: I do have one more request from you. On our podcast we have this motto and it says, after a diagnosis comes hope." If you were to fill in the blanks, what would it be? After a diagnosis comes?

Oya Gilbert: Ooh, that's a good one. You put me on the spot. I mean after diagnosis comes a new journey; I would say. A journey that doesn't have to be filled with despair or dismay because there is still a lot to live for, no matter what the doctors are telling you or what your cancer is.

Like I was saying before, it's made me acutely aware of everything around me. So I sit outside and things I would never do before, I listen to the birds. Things that we take for granted in life, that's what life after diagnosis has meant for me is not taking for granted the things that we normally take for granted that are very simple and everyday stuff, whether it be using the bathroom without assistance or doing



something magnificent like hiking up a volcano. It's just go live your life and treat it as such a, where you're not promised tomorrow. You're not promised the next five minutes. So all those things that you said you were going to do or maybe next time, just go do them and just live your life.

Alicia: Awesome, we couldn't agree more. Oya, thank you so much for joining us today and sharing your story. You mentioned earlier that one of your doctors said that the goal of treatment is to provide improved quality of life until technology catches up. And that is our hope and prayer as well, and that is why LLS invests in research because we want to hear one day that the cure for cancer has been found.

So thank you so much for joining us today.

Oya Gilbert: Thank you, ladies, and it's been an honor and a pleasure.

Lizette: The pleasure is all ours.