

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Making The Decision To Live: A Myeloma Story'

Description:

Join us as we speak to Tim Cooper, a multiple myeloma patient and caregiver. In this episode, Tim discusses how he was diagnosed with myeloma after sustaining a neck fracture. Unlike many patients, he was familiar with myeloma, as his mother had been diagnosed with myeloma years prior.

After multiple treatments, including chemotherapy and stem cell transplantation, Tim is doing well and enjoying life. He finds that sharing his story is therapeutic and encourages other patients to keep pushing forward and find hope after a blood cancer diagnosis.

Transcript:

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

Jesse: I'm Jesse.

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

Elissa: Today we will be speaking to Tim Cooper, a myeloma patient diagnosed in July of 2021. Since that time, he's had multiple treatments, including chemotherapy, radiation, and neck surgeries for fractures that occurred due to the myeloma. Tim has been able to take advantage of the LLS Copay Assistance Program and is now sharing his story to help others going through this difficult diagnosis.

Welcome, Tim.

Tim Cooper: Hello.

Elissa: So, let's start with your diagnosis of myeloma. Could you share a little about what multiple myeloma is?

Tim: Well, multiple myeloma is a blood cancer, and the way I was diagnosed, it started with an injury which led to me getting x-rays done. And it was determined that the myeloma had attacked my blood and my bones, so it can attack your bones as well. My mom has the same cancer, so I was familiar with it. The cancer caused a fracture in my bones, and it weakened my bones. So, it was in my neck and in my lower back; it's still there. So that's how I found out what I had.

Lizette: Tim, you just mentioned that your mom also has myeloma. Did the doctors say anything about if it's hereditary or anything like that with your family?

Tim: We did discuss that and it's normally not. It's extremely rare if that happens and it really couldn't be tested to determine whether it was hereditary or not. It's a coincidence. That's really all it was. There's no strong data that show that it's hereditary at this point.

Lizette: Right. That's definitely what has been shown that it's typically not hereditary, but I think now because there's more families that are getting myeloma, they are now starting to really research to see if there is that hereditary component with myeloma at this time. So, it is very interesting that your mom has the same diagnosis.

Tim: Yeah. The evolution of it, like with treatment and with everything else, they're discovering, I guess, more connections with it. I always thought that it was. I just never thought to go further trying to get tested to see if it was hereditary or not.

Jesse: Tim, were there any signs or symptoms besides the neck injury that led to your multiple myeloma diagnosis?

Tim: No, nothing at all. It was a shock. I knew the injury that I got was going to require neck surgery, and it was a required emergency surgery. But the neurosurgeon



said, "Yes, you have to have the neck surgery and it's urgent, but you also have cancer."

Jesse: Oh.

Tim: And I was like, "What?" I said, "What?" three times and then I broke down. After I got off the floor, I got back up, and we discussed it. And he said, "The cancer is attacking your bones in your neck and in your lower back." So, he said that day "I need you to go right now to the hospital and check it." I said, "Today?" He's like, "Today."

Jesse: Wow!

Tim: I left his office, and I went to the hospital. I got a bed that evening, and I was in the hospital having surgery that Friday. I had two surgeries. They had to put a metal plate in the front of my neck to stabilize it because if I hadn't had the surgery, I'd be paralyzed from the neck down.

Elissa: Oh goodness.

Tim: So that's why that was the urgency to have that done. Then four days later, had the plate fused. It was called a thoracic fusion. They went in four days later and fused the back with titanium screws and rods to the front and that's what saved me from being paralyzed.

But what was even crazier the next day I got there, the oncologist at that point, thought I had possibly two more cancers.

Jesse: Oh wow!

Tim: They saw lesions on my organs. We thought they were tumors. I was like, "Wait a minute. Not only do I have one cancer and I have a life-threatening paralysis fracture in my neck, but I may have two more cancers?" So that was, again, overwhelming day, two in one week. They came back the next day. They did tests on



it, and they weren't tumors; they were lesions. Thank God it was only just the one cancer to deal with, you know, as opposed to having two more and dealing with the neck injury.

So, that's how it came about. It was just that quick. There was no sign at all. I go to the doctor every year for a regular physical, and there was never a sign in my blood or anything that they saw that could've picked this up. How do you look for that? I don't know how you look for that in bloodwork, in your test results whether they saw anything, but no one did.

Elissa: Wow! Now, these all came about and were seen with scans that you had done for your neck fracture? They had seen that the cancer was throughout your neck and in other places.

Tim: Through having MRIs and a CAT scan to determine where it was, I guess they put the dye in your system and like a Christmas tree it lights up.

Elissa: Wow!

Tim: And they saw it in my neck and a large part in my lower back. So, after these surgeries, I had to go into radiation treatment right away. I did two weeks of that every day. And after that was completed, the next thing was to start my chemotherapy treatments going forward. We thought the neck surgery was successful, but after a few months, I went back for a follow-up, and we saw two of the top screws had come loose. They said, "Well why is that?" So, what he did was gave me a more restrictive brace called a SOMI (Sternal Occipital Mandibular Immobilizer) Brace. And it was very mechanical looking, so I was called the *Six Million Dollar Man* by my friends.

Elissa: Oh no!

Tim: What's even funnier, I lost my voice. They were calling me Mickey Mouse. They were calling me Mafia Don. They were calling me Mr. Bill. Any name. My friends

were relentless, which I needed that. It was just the sarcasm my friends had, it was just so valuable to keep me here and realizing you got to make light of it as much as possible to not live in that dark space.

And they saw that right away to pick me up, to keep him here, not treat him with kid gloves. They were praying for me, and they were sympathetic; they knew that I needed that normalcy going through that. That was probably in September that we saw the screws had dislodged. By November, the brace did not help those screws come back to being fused, so I had a third surgery. But I couldn't have it until after I had my stem cell transplant.

Elissa: When you finally got with a myeloma oncologist, did they talk to you about how common or how rare that is to have neck fractures as a result of myeloma? What did they say about that?

Tim: Honestly, we didn't discuss the correlation with the neck fracture to the cancer. And that's a great question because I never asked her that that I can remember. It was more about treating the cancer than how it got to the bone, but I believe that it's not uncommon. I mean, the cancer itself is rare. You may get 35,000 cases a year of myeloma. It's been the trend so far. I don't remember discussing that correlation. So, I'm going to ask her.

Elissa: That's a good plan.

Jesse: Well, we're happy that we brought it up today.

Elissa: It's good to be educated about your disease and, hopefully, it will encourage other listeners to ask their doctor questions and find out information.

Lizette: Now, Tim, you mentioned that there's various treatments that you've had. Can you tell us a little bit more about the treatments you've had for the myeloma?

Tim: Okay. The first one, again, was for the radiation. So that was maybe two weeks after the second surgery. That started in late August and September of last year. I was going there, every day, not on the weekends, obviously. But I would go there. They would just put me in the machine, and they would rotate around me, I guess do the laser beam. It was like five minutes, and I was done. It was a quick process every day to go through it, but the intensity is what caused the bone to weaken and to deteriorate, which caused the screws to come loose in my neck.

Elissa: Oh!

Tim: I don't know if hindsight would they have done the radiation prior to the surgery? I don't know. But that's what caused those initial two screws to dislodge.

Lizette: So then after you had the treatment, you had chemotherapy?

Tim: Yes. I was getting what's called Velcade®. I was getting an abdomen shot. It would alternate left or right side every visit. And initially it was twice a week, it started from maybe late September up until the end of January. I was going twice a week and getting a shot every day.

They do bloodwork to make sure my numbers were safe to still take the Velcade shot. As they came back positive, it was approved to have the shot administered, and that was twice a week for almost five months. And then once a month, I also got a Zometa®. It's a drip for the bones. I would get that every four weeks as well.

And then I also started on a pill, Revlimid® where, it was 21 days on, 7 days off. I initially started with that, and it caused me to have chalazion on my eyes. So, they were on the inside of my eyes, not on the outside. I was like, "One more thing." It caused my eyes to swell like I was in a boxing match, and I lost.

Lizette: Wow!

Elissa: Could you explain a little bit to our listeners who might not know exactly what that is you're describing?

Tim: So, a chalazion grows inside of your lid, and the Revlimid, the reaction from that caused me to have a chalazion. It is just like an inner stye, basically. And so, the medication I was taking gave me that side effect and it lasted for several weeks. And it blocked my vision. It got harder to see, obviously. I went back to the doctor. We tried a variety of things. And, finally, "Well, let's stop the Revlimid for right now and see if they go away." And they did.

At that point, we stopped the Revlimid and waited till the chalazions were gone and then worked toward what would be the next step we could use. The variety of drugs you can use, but the Revlimid was the most effective in treating my type of cancer. That's why they chose that initially. But what happened was when I started again, they gave me the half dosage, which I'm still doing now, and they didn't come back. It was just too strong, I believe, of a dosage that caused that reaction in me that brought up those chalazions.

Lizette: One of the things that you're saying is very important is that you brought up to your doctor that you were having a side effect. A lot of times patients are not comfortable letting their doctors know and what you just said that there's other options for treatment. Especially with myeloma, over the past ten years, there's been a lot more medications, a lot more treatments available now to myeloma patients. So, for patients to feel free to talk to their doctors and their treatment teams about their side effects.

You keep saying, "One more thing," you know. Your journey is a complicated one, Tim. So, it's great that you were able to communicate with your doctor.

Tim: I think too part of it was as well I was willing to try different things. With the chalazions themselves, I went to see an ophthalmologist as well, and he tried to diagnose it. And he gave me an ointment, and I got this pill. So, we went through a

lot of different things to finally come back to, let's stop the Revlimid and see if that stops it. And it did. I think a lot of times people aren't patient enough and want to try to investigate the options of what it could be. If you want to solve the issue, that's part of the risk. There's always risk either way. If you don't do it, you could risk losing your eyesight. Who knows what that could be, but the other side is they can discover what it is and find the right root cause and solve the issue.

Lizette: Right, definitely. Now you did mention transplant. Did you have an autologous, from your own cells, transplant for your myeloma?

Tim: I did. It was actually an amazing process to witness the harvesting of the cells. They put it through this machine. To watch your blood filter through this machine out of your body and then come back into your body. It's at small doses but you don't feel it. I felt a little weak as far as the only side effect.

Luckily, when I had the transplant and the harvesting process, people's reactions and results vary, sometimes you have to do it twice because they don't get enough stem cells out of your body the first time. So, luckily, I was able to get enough stem cells, it was 11 or 12 million to use. It was an eight-hour process and you're there all-day laying there with tubes in you. If you move, this machine beeps, that one beeps, they all beep. So, you really have to just lay there as a statue somewhat and go through the process.

I thank God that I had the technicians, the nurses, the surgeons, the nurse practitioners because they cared, it was genuine, and it made everything that I went through at every step of the way that much easier.

Jesse: Now, you seem to have gone through quite a lot since being diagnosed with myeloma just over a year ago. Just listening to your story now, I personally cannot believe it's only been a year, because you have gone through a lot. What do you wish you would have known as a newly diagnosed patient?

Tim: I think that it boils back to regular checkups. Now do you get checkups for cancer normally? I mean do they test for that? Do those signs show up in your bloodwork? I don't think so initially. I got a physical every year, so should you go every six months? Maybe at a certain age you go more often to track for like a prostate cancer or other cancers like pancreatic cancer, for example. That doesn't show up until you almost succumb to it in some cases.

Jesse: Yeah.

Tim: With science improving, hopefully, they can diagnose these things sooner and catch them earlier, but it really boils down to you going to the doctor regularly is the most important thing we all need to do. Get your mammograms, get your prostate exam done. As you get older, things stop working as fast, right.

Jesse: Yeah.

Tim: I have been in good shape for most of my life so when I had the injury, I was like, "I just have a crick in my neck, it's not a big deal. Lifted too many boxes this one day; it'll go away." Initially it did. Then it stopped going away and then I couldn't get out of bed. I said, "Wait a minute this is not normal."

Jesse: Yeah.

Tim: And so that's when I said, "Let's go to the doctor, make sure it's not your heart." I got an EKG done twice to make sure I wasn't having a heart attack because my arm was tingling, my hands were tingling, and they went numb. So, I knew it was something severe in my neck that was happening. We saw that the actual vertebrae collapsed, and it was a large vertebrae and that's why it was so imperative to have the surgery. So, again, it comes back to getting regular checkups. Communicating with your doctor knowing what questions to ask, and if you don't know what to ask, have an advocate with you because so many folks get overwhelmed.

Jesse: Absolutely.

Tim: And they don't know what to ask or what to say. And thank God I was coherent enough and smart enough, I think, to ask the right questions and get the right answers. So far so good.

Jesse: And as you've mentioned, it's really knowing your body as well. As you said you noticed-

Tim: Absolutely.

Jesse: -the pain wasn't going away and being proactive for yourself and your health.

Tim: When you get over 50, your body talks to you a lot more. And you need to start listening to it because it'll tell you when you're tired, when you ate the wrong thing.

And after this, I listen all the time for little things, and I track when I have something, "What did I eat, what did I have that day?" to see if this thing may have caused this reaction. You got to really listen and know your body and be proactive. If you can't find an over-the-counter solution, right? Seeking your doctor's advice and their expertise to help you figure out what it is.

Lizette: Yeah, that's really good advice, Tim. Now since you're also a caregiver to a myeloma patient, and you have myeloma, you're coming from a whole different perspective. How has that made you a better caregiver to your mother?

Tim: Well, I tell you I understand a lot more. My journey with myeloma was not as severe as hers. She was older. She got it at 62. She's had it for 16 years now. She's in remission right now of that, but she has leukemia now.

Lizette: Wow!

Tim: When I was getting my stem cell transplant, I found out she was in the hospital. And they didn't want to tell me to affect my recovery. But they said, "Wait a minute if something happens and we don't tell him, he's going to be furious." So, my sister

called me and told me and another gut punch. I said, "What more can she deal with? She's in remission from myeloma and now she has leukemia."

What we found out was that you can be diagnosed with leukemia after you have myeloma. It's just the reality of, what my life's going to be for the rest of my life. I'm going to have cancer for the rest of my life. I understand that. And so, again, be proactive. What can I do, what's in my power to make sure that I can do whatever I can to still be here? Whatever that means. And so, I have to now think about that as well with her.

And so as far as what I've learned from her. I've watched her strength. You have to have the will to want to live, and she fought. We almost lost her several times over the last 16 years. She's had two or three stem cell transplants.

Jesse: Oh wow!

Lizette: Wow!

Tim: So, to watch her sink down and lose her hair and to lose weight to continue to bounce back is two things. It's her faith, strong faith that we've always had as a family, and her will to want to live. And she always said, "I want to live." That was an affirmation she made all the time, "I want to live." She went by her faith and trusted her doctors and her own will and our support. It brought her through. She's a tremendously strong woman, and I'm praying she will be able to fight.

Jesse: At the beginning of the podcast, Elissa had mentioned that you received LLS financial assistance. Has that been beneficial to you, and would you recommend that to other patients in similar situations?

Tim: It has, and I would. Again, it comes back to having a good advocate in your corner. It started with my social worker. She was able to inform me of different things and programs that were available that I could use that would help me financially



because, again, so many folks go under financially because of not knowing what your resources are and having an advocate.

Between getting the travel expense card that I got, getting gas cards from her, she was able to get me so many different things through your organization that helped me not worry about a financial burden. That's the last thing you need to worry about when you're going through a life-threatening illness is how you're going to pay a bill.

And that's a bigger conversation, as far as healthcare in general. But I think that knowing that she was there and got me the right resources that I needed at the right time. And so that was the power of it, speaking up and asking and knowing what to ask and then having a good advocate you could communicate with is going to do their job-

Jesse: Yeah.

Tim: -and help you. And some didn't work out. But I went through, I called several organizations. "Nope, it's gone. Nope, it's gone. It's already-" I said, "The window opened up yesterday, it's gone already?" I mean so if you, if you're not on it again, you've got to be dogged with it because a lot of it is on you too. I can't depend on someone else to do it for me. My mom's social worker is phenomenal. I mean she will go after stuff and tell her and get her everything she can possibly get. And she's phenomenal and mine is great too. She gave me a ride to the doctor last week, "I'll pick you up. No problem."

Elissa: Aw!

Tim: If everyone was like that, it'd be a lot better, but the reality of it is every human is different. And so, I just thank God that I had someone and several people in my corner that cared about me.

Elissa: Well, Tim, I'm so glad that you were able to get the financial assistance. For our listeners who don't know, the Copay Financial Assistance not only covers copays

for your medications, but it can also cover your lab costs, other costs and fees associated with your cancer treatment. And so, it can be very helpful.

And like you said, unfortunately, those siloes do close and open. They're given a block of funding and then they might close for a little bit but then they open again and so you just have to keep watching out.

But I'm so glad that that was available to you and has been beneficial. And we talked to you before the podcast and you'll be applying for your second year of it soon, so that's wonderful. And we'll have information at the end of the episode for our listeners to get more information about financial assistance, no matter what diagnosis.

Lizette: Yeah. And I wanted to commend you on your communication and persistence. You keep bringing it up, but it's so important that you felt comfortable to ask, to bring up topics, bring up issues and keep that communication going. And I know that it probably has also helped you with your career.

Now you were working up until your myeloma diagnosis, correct? So how has the diagnosis really affected your career?

Tim: Well, I tell you I stopped completely. And it made me realize that at this point I was tired of working for somebody else. So, my goal is once I get past this and I'm healed and feel more strength in my neck, I'm going to start my own business.

Jesse: Oh!

Elissa: I love it!

Tim: I want to work for myself. I have enough experience. I think I'm smart enough to be able to do certain things where I can help someone. I want to thrive-

Elissa: Yes.

Tim: -not just survive.



Elissa: That's great. Sometimes priorities shift after something like a cancer diagnosis. And speaking of thriving, you are still trying to also maintain a good quality of life in other ways. Could you tell us some of the things that you are continuing to enjoy doing while living with myeloma?

Tim: Well, I started doing *DoorDash*.

Jesse: Oh!

Elissa: Oh!

Tim: So, I needed some more residual income because with disability, you get a limited amount of money and-

Elissa: Yeah.

Tim: -I wasn't ready to start this business yet, so I had to get some more money in my pocket.

Jesse: Well, Tim, I have thoroughly enjoyed the conversation today and our team appreciates you being so open and vulnerable. We know it's not always easy to share your story. As you are aware, our team found you after you did a series on podcast episodes for your local hospital. Has that personally helped you to share your story while also helping other patients and caregivers?

Tim: Absolutely. That was my therapy because my doctors initially had to say, "You know what, Tim, you should speak to us about adding a therapist."

And, yeah, I went through depressive moments on my own. I lived in a dark place for a while, but I had a great support system that could bring me out of that.

And so, I think that podcast and that series of telling my story and doing my videos was my therapy. And I had great interviewers, and I'll say Josh Jarman and Gina



DiPietro as well as Robin Baltimore and Roland Wilkerson were great interviewers. They valued my story, they listened, and we're friends now.

Jesse: That's great.

Tim: I think going through this experience-

Elissa: Wonderful.

Tim: -that they were my therapy. What they've learned from me, and they said that I've affected their lives. That was not the intention, right. It was more about me telling my story and how they identified with it in their own families, things that they've seen. So, they've helped me, but I've touched them too. So that's why I said, "You know what, Tim, it's not just your story; it's the message that you've been able to tell through these podcasts, through the videos and the articles that is an important message to get out to a larger audience, if you can."

Jesse: Well, you have definitely inspired me, so thank you.

Tim: You're welcome.

Elissa: Now on our patient podcast home page, we have a quote that says, "After diagnosis comes hope," speaking of inspiring other people. So based on your cancer experience, how would you complete that sentence, "After diagnosis comes"?

Tim: Comes life. I mean it comes to the decision to live and to not be consumed by it. I think a lot of folks hear the C word and think it's over. That's what I thought. But after reevaluating and looking at my mother was my direct line of reference.

She wanted to live, and so it's about, yes, you've been diagnosed with this now, but how do you deal with it? What are your next steps? And for me, it was to not just survive but to thrive. So, I would say after that comes the ability to thrive, but you have to embrace that. If you're not willing to embrace that, then it's not going to come to you. And, and I'm still walking through that journey. As I say these things,



it's reaffirming to me of what my purpose is and how I'm going to do this myself. But also, how can my story help somebody in a regular conversation, doing an article, do a podcast. So that's how I would answer that question.

Elissa: That's perfect. Well thank you so much, Tim, for joining us today and, again, being so willing to share your story. We can see you even though the listeners cannot, and we have seen how just sharing has brought you to an emotionally vulnerable place at some points in our conversation and we really, really appreciate you sharing with us. You had quite a unique journey so far through myeloma and we're glad to hear that you are doing well right now and your mother is pushing through and wants to live and has that hope to push her forward.

So, thank you, again, so very much for being here with us.

Tim: Well, thank you. It's been a pleasure to be a part of your podcast. Thank you for inviting me. I really appreciate that.

Elissa: Thank you.

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.

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