

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Family Ties: Navigating Multiple Myeloma Together'

Description:

In this episode, we speak to a myeloma patient and her teenage daughter about the impact that myeloma had on her family. Lynn Steele, a social worker and Information Specialist at LLS, then joins us to share tips and resources on how families can navigate a cancer diagnosis together.

Transcript:

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

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

Elissa: Today, we will be speaking to Ashlie and Emma D'Andrea. Ashlie was diagnosed with multiple myeloma in April of 2023 after a routine physical found abnormalities in her bloodwork. She immediately started therapy and had an autologous stem cell transplant in October of 2023. She is now on maintenance therapy and has recently been able to return to work as a teacher's assistant.

Her daughter Emma is joining us today to share about the impact that a myeloma diagnosis has had on her family, which also includes her father and 13-year-old sister.

Emma was 14 and a freshman in high school when her mother was diagnosed. While navigating this change in her family's life, she has remained very active in life and school.

After we speak to Ashlie and Emma, we wanted to hear from a licensed social worker to get advice for families with young or teenage children navigating homelife after a parent is diagnosed with cancer. Stay tuned for that discussion later on in the episode.



Welcome Ashlie and Emma.

Ashlie D'Andrea: Hi, thank you for having us.

Elissa: So, Ashlie, let's start with your myeloma diagnosis. Could you tell us about how you were diagnosed?

Ashlie: Sure, like you said, I went for a routine physical. My white blood cell count was high, and I was severely anemic. Those were the two things that showed up in my bloodwork that alerted my doctor, so he ran a couple more tests which came back showing that there was a possibility that something was wrong.

So, he immediately got me into see a hematologist with his group who knew from the other tests that my doctor did that he was pretty sure it was multiple myeloma. And then they did the bone marrow and follow-up tests just to confirm it.

Elissa: So, we all know that hindsight is 20/20. Now looking back, were there any signs and symptoms prior to that abnormal blood work?

Ashlie: So, I had weird things going on. I was getting nosebleeds, which for an adult in her 40s, you don't typically get nosebleeds like I was getting. They would wake me up in the middle of the night So, I went to an ENT [Ear, Nose and Throat specialist] for that. They thought I had some sort of staph infection in my nose, so they had me on antibiotics.

I had a weird pain, like a pulling pain in my chest, but I thought I just pulled something working out. When I went for my physical, they did an EKG though and said that everything looked normal. So, I didn't think anything was wrong there.

So, I just had like little things. I had some pain in my foot. I went to the foot doctor. So, for every little thing that was wrong, I felt like I went to that specific doctor, never thinking that it was something like this.

Ashlie: But, once they confirmed the diagnosis, then all of those things made sense because eventually myeloma gets into your bones, and it affects your joints and things. So, it started to all make sense after I figured out what was wrong with me.

Elissa: Yeah, I think that's really common for patients to have just little symptoms, signs here and there, and they always attribute it to something else, right? It's just a little thing like your foot or a headache or nosebleed.

Ashlie: I did. And I kept putting off going for a physical because my cholesterol was always high; and I didn't want to hear that "Your cholesterol's high," and so I put it off. I was maybe six months later than I should have been for the physical, and I remember when my results came back, I was so happy that my cholesterol was low but I didn't even look at anything else because I didn't think anything else was wrong, and I was just focusing on that.

Lizette: Right. And after your diagnosis, what were the treatments that you had? First of all, you were happy that you knew what was going on, right? Was that a relief for you?

Ashlie: Well, it kind of all snowballed. The morning that I woke up that I was supposed to go for my PET scan, I had blurry vision in one eye. I believe it was my IgG levels were dangerously high, and they were causing blood clots. I actually ended up having a blood clot in my eye. So, the day that the doctor confirmed diagnosis, and I went for my PET scan, I left the doctor's office and was about to come home; and he called and told me that I had to go to the emergency room because my IgG levels were dangerously high and they had to do something. It was called plasmapheresis where they put tubes in your neck; and they basically take out some of your blood and then infuse it with a medicine to try to thin it out and regulate those levels.

Everything happened so quickly. I didn't even have time to really process what was going on. The girls did not know at that point. We just told them Mommy has

something wrong with her blood, and we're going to try to figure out what's going on. And we just left it at that.

I ended up spending a week in the hospital after that. It wasn't even like a relief. Like this is why I was having bloody noses or my chest hurt. It was more like just shock because it just snowballed so quickly.

Elissa: When did you decide to tell your daughters?

Ashlie: After I spent that week in the hospital. That day that we came home, we told them.

Lizette: And, did they start treatment right away for the myeloma?

Ashlie: Yes. Well, when I was in the hospital, they gave me one dose of chemo. Once they sort of regulated everything, then I started right away on the therapy.

Lizette: So, were you inpatient for a while you were getting treatment?

Ashlie: When I first got diagnosed, I was inpatient for a week. Then I was home, and I was going every single week for the therapy that they started me on. Every Tuesday I was going and through August. They sort of had to regulate my numbers and get things where they wanted them to be before they can proceed with the transplant. They had to, try to regulate the myeloma so that they can use my own stem cells for the transplant.

Lizette: Sure, so you got an autologous transplant from your own cells.

Ashlie: Correct.

Lizette: And how was that for you?

Ashlie: I mean it went well. They collected the stem cells. They actually got enough for three transplants, which is a lot from what I'm told. Some people have a hard time

even getting enough for one. So, I had one in October. Hopefully, I don't need another one. But just in case I do, they have enough for two more.

Probably the toughest part of this whole thing was, having a transplant. And it wasn't the actual process of the transplant, it was more being in the hospital. I was there for 16 days, away from, my family and confined to one floor in the hospital for that long.

Lizette: Right. And did they talk to you, Emma, in regards to knowing why your mom had to be inpatient for the transplant?

Emma D'Andrea: My dad was there with me and my sister through it all and I could talk to my mom as much as I could. I would Facetime her, but I felt like I was so young to understand everything that was going on. So, I was kind of just like, "Oh, that's what it is." But I never really understood it.

Lizette: And you were how old?

Emma: I was 14.

Lizette: Yeah. A lot of times it takes a lot of explanation about why during the transplant and after the transplant you may not be around as many people just because your immune system is so compromised.

After the transplant, what have you done, Ashlie? Are you on maintenance therapy?

Ashlie: I am. Like you said, I was isolated for a while after I came home from the hospital. You don't realize how many restrictions there are even with food. You cannot get food, you can't order out because you don't know how the food is prepared or how well things are cleaned. So, there were tons of restrictions, but, as my numbers went up, they started to ease up a little bit.

But I spent almost six months home, and then I went back to work on April 1, finally. Still supposed to technically wear a mask. I work with young children, so I try to wear it when I'm in direct contact with them. But when I'm with, adults or I walk out of the

classroom, I try to take it off just to give myself a break. I still have to be careful. I can still pick up things more easily than anyone else can. So, it's definitely a lot.

Lizette: Sure. And have you had any side effects from treatment?

Ashlie: No, I actually tolerated it all very well. When I first started my therapy a year ago, I constantly was getting fevers. Those were the worst side effects. I was exhausted. Every time you have a fever, you have to go in. They have to do a fever workup to make sure it's not an infection.

They don't see that a lot, I guess, with the therapy that I was getting, so they were more concerned that it could be something else which it didn't turn out to be anything else, thank God.

So, , I had to deal with that. But now the therapy that I'm on, the maintenance therapy is a lesser dose of everything, so I'm tolerating it fine.

Elissa: Good. That's, good to know and that you've had minimal side effects and then you're back to work, which is so exciting. Well, I mean most people would-

Ashlie: No, it is.

Elissa: -find it exciting.

Ashlie: It's exciting, and Emma was very excited for me to go back to work too.

Elissa: Oh, I'm sure. I'm sure.

Now Emma, having a parent or close family member be diagnosed with cancer can be really difficult. How did you initially react to your mom being diagnosed with myeloma?

Emma: Well, I remember being in the kitchen, and my mom, she just started crying. And I was like something's not right. And then my dad started telling us, and I just

broke down. No one wants to hear that their mom is sick. That's the worst thing that you could ever hear. And so, I started crying and my dad just started crying. My younger sister was the only one who wasn't crying. And I was actually surprised that she was just standing there with the most shocked look on her face. And then, everyone started crying, and it wasn't easy at the time, but now, things are somewhat back to normal for the most part. So, it got better over time.

Elissa: Now, you were finishing up your freshman year in high school, right?

Emma: Yes.

Elissa: How has your mom's diagnosis impacted your life?

Emma: Well, there wasn't really so much freshman year that it did. I think it was more sophomore because at the time freshman year was almost over. But things haven't really changed that much. Except for when she was in the hospital for two weeks after her transplant, we didn't see her as much because she was there. But I would always Facetime her, and I'd always talk to her.

But being on like a cheer team and having all those competitions, she wasn't there for most of them; but I know she was always watching. And I always had a bunch of other family members there supporting. But I always knew she was there, so it wasn't really that big of a difference.

Elissa: I'm sure it was hard to have her in the hospital and not being able to go to those things. So that's good that you were able to Facetime her and still keep her very involved and having her feel like she's still there.

Emma: Yeah.

Lizette: And Ashlie, as a mother and wife, how has it been for you during treatment where family dynamics may have shifted or changed?

Ashlie: I have to say we're lucky that we live close to both my parents and my in-laws. And my sister-in-laws have stepped up tremendously. I mean, they took care of my girls like they were their own when I was in the hospital. Everybody really helped as much as they could; and, I think we're very lucky that we live so close to everyone, and we were able to have the help that we had.

When I was in the hospital, my husband came down every single day; and, he wouldn't have been able to do that if we didn't have the help that we had from our family members. Even just cooking dinner and driving the girls to practices and picking them up and getting them where they had to be, they just helped tremendously.

I don't honestly know how we would have done it without them, because he wanted to be there with me. I wanted him to be there with me; and, it would have been hard if we didn't have the help that we have at home with children who can't drive themselves where they need to be. So that helps a lot with keeping things as normal as they could for the girls.

Lizette: A lot of our patients have said to us that they find it hard to ask for help. Did you find it hard to ask for help?

Ashlie: I did not find it hard. They were all so willing. I still ask for help sometimes when I need it. You know, now that I'm back at work, I'm not always there to take the girls where they need to be. And I've always asked for help.

But when I was unexpectedly admitted to the hospital last April, everyone was there; and I didn't even have to ask. So, when I knew I was going in in October, I knew they would be there. I just had a giant calendar, and I wrote down everything that the girls had for the month; and they just figured it out and they took care of it.

So, no, I don't find it hard to ask. And I think also knowing how willing they were to help made it easier.

Elissa: I think it makes a difference too to have that close family that just steps in and just does whatever needs to be done. I'm glad that you had that level of support.

Now, Emma, with your mom being in treatment, how has it been for you as a young caregiver?

Emma: I still just can't even like think it's real. It was hard to process things at first; but as treatment kept going, I was like, this is going to be the normal for a while, so I kind of just accepted it. I guess, changed as things went on.

Elissa: Do you feel like your role in the house has kind of changed a little bit?

Emma: Not really, to be honest. I feel like mom and dad kept trying to make things feel as normal as possible for me and my sister while everything was going on like towards the beginning, that nothing really feels different now.

Lizette: And Emma, what did you feel the most, kind of that emotional impact? Did it hit you right in the beginning when you all started crying, or did it happen after she got treatment and when you saw that she was in the hospital?

Emma: I feel like both. When she was in the hospital for that week, when me and my sister didn't really know what was going on, I was just overwhelmed, because I wanted to know what was happening.

My dad's a really bad liar; so, when he would come home and he would be like, "Oh, it's just an infection," I knew he was lying. I knew he was not telling the truth to me or my sister. So, I was just like, "They'll tell us eventually. They're not going to hide something from us forever. Like that's impossible."

So, leading up to when we actually found out, I feel like was the worst because I was just waiting for something bad to hit me. But, when she was going through treatment and everything, I was obviously still a little sad because, I hate to see my mom in like pain or just sick or anything like that.

So, it was just saddening. That's the only word I actually have to describe it. But she's healthy now, and she's feeling better all the time. So, it just feels normal now.

Elissa: Do you have any fears or anxieties thinking about the future and how things will go?

Emma: I'm just going to like, she's going to have to go to the hospital for a while then because that was the worst part of everything, not coming home and seeing her everyday not getting to kiss her goodnight had to be the worst part. But, as of right now, everything's fine. I'm not really thinking about what could happen tomorrow.

Elissa: Good. That is a good way to live. Live in the present where your mom is doing very well, and I like that. That's a good way to live.

Now, Ashlie, what has been the emotional impact for you, and what you think your family is after the diagnosis?

Ashlie: I wasn't ever really a person to show emotion. My husband always used to joke that I didn't have a heart or that it was made of ice. So, it was just a big running joke in our family because I wasn't one to really express things.

So, I guess people have seen, another side of me since all this has started because it takes a toll on you and your emotions show, whether you really want them to or not.

Elissa: Yeah. Now, our final question for both of you today, on our patient podcast homepage, we have a quote that says, "After diagnosis comes hope." What advice would each of you give to families, particularly those with teenagers or young children, after a diagnosis of myeloma?

Ashlie: For me when I was first diagnosed, I did not even really understand what it was. But after talking to so many different nurses at the hospitals and them telling me how far they have come with the things that they could do for this disease, that's literally where I got my hope from. There have been so many advances in the things



that they can do for this that that's where I've gotten my hope from is just hearing that. And obviously, for my girls that I just want to be here for them as much as I can and for as long as I can. So, that's where I got my hope from.

Elissa: Emma, what about you?

Emma: As a teenager, I would say, just always look at the bright side of things and just take it one day at a time. I feel like as a kid, our first natural instinct is always to be like what's the worst thing that could happen? But, I just feel like that's the worst like possible thing you could do.

My mom was sick, but I feel like things could have been way worse than they actually went. You just have to take things one day at a time. One day she could have had a fever or something, and the next day she could have been laughing and smiling and you wouldn't even think anything's wrong. So, you really just have to stay positive and hopeful.

Elissa: That's very good advice from both of you. I love the message of hope where research is concerned and how many new treatments are coming out with the great possibilities for the future. And then, Emma, of course, talking about really living in the present. I love this so much.

So, thank you both so very much. I think this was so helpful for myeloma patients and their families that are listening to see how another family has gone through this. And so, we really appreciate both of you being here with us today.

Ashlie: Thank you.

Emma: Thank you.

Elissa: We'd now like to introduce Lynn Steele, a Senior Information Specialist at LLS and a Certified Oncology Social Worker. Lynn has over 20 years of oncology social

work experience that encompasses all aspects of cancer care and has 40 years of experience in the field of social work.

In her current role, she assists cancer patients, caregivers, and family members from initial blood cancer diagnosis through treatment and survivorship. Lynn considers it very important to meet patients and family members where they are to provide a nonjudgmental atmosphere of open communication, enabling patients and caregivers to become their own best advocates. Welcome Lynn.

Lynn Steele, LSW, OSW-C: Hi. Thank you so much. So nice to be here with you today.

Elissa: Thank you. So, we just finished speaking with Ashlie and Emma about their personal experience as a family after a myeloma diagnosis. What are issues that patients may have as they parent after a cancer diagnosis, whether they have young children or slightly older, like Ashlie's 11- and 14-year-old daughters?

Lynn: Yes, so they can really have a number of different things that might come up for them, just depending on who they are and what's going on. So, it might be work concerns or school concerns for the children, learning about the diagnosis, maybe never even hearing of the diagnosis. That can also happen when people give us a call.

Elissa: Yeah, particularly with blood cancers.

Lynn: Yes, absolutely.

Lizette: And when you speak to patients and caregivers, what typically do you speak about to help them manage treatment and parenting at the same time?

Lynn: Right, that can be a little tricky. And so, really just providing the parents an opportunity to talk about what they need and what challenges they might be facing with their children. As you said, it could be different ages, so there might be different challenges for the little ones as there would be for teenagers. Sometimes, teenagers

might want to try to take over things or maybe they feel worried about finances. So, really just meeting them where they are. What's happening within their families, and how would we best be able to help them as they're learning about the disease or trying to process treatment? Even, sometimes, they have to be far away for treatments, so that can be a challenge too.

Lizette: Right, and Ashlie mentioned earlier that she and her husband waited for a little while to tell the children about the myeloma diagnosis. Do you have suggestions on talking to children about cancer and what might be ahead for their parent or family?

Lynn: I think letting the parents know that they know their kids best, they know their family best, and really starting with that. So, what did they think would be most helpful for their children, and how much do they want to tell them?

I know here at LLS, we do have a fact sheet for talking with children; and there's some other resources that we know about that we could guide them to other organizations in what to tell the children, how to tell them, how much to give them at a certain time.

Elissa: That's great. Now let's discuss the family for a moment. What are struggles that the primary caregiver or even children may have after a parent is diagnosed with cancer?

Lynn: So, I think sometimes it's employment struggles for the primary caregiver or someone within the family. Are they able to continue working? And even for the patient themselves, was the patient employed full time and now are they able to work? Do they have any disability through their employer if they were employed? If it's going to be a long time of treatment, would they be eligible for Social Security disability? What insurance concerns? Sometimes they have these financial concerns as well, so really looking to some of those more practical kinds of things. Maybe even transportation to and from their appointments. And so, there's those practical concerns that might be happening.

Elissa: Yeah, I could imagine potentially losing an income or going down to part time for a normal two-income family with children, that would be just really difficult.

Lynn: Yes, and if it's a single parent family being able to provide care for the children at home, who will watch the kids? Who's going to get them to and from activities? How will they manage that? Those are those practical concerns, as well.

And then, the emotional piece because I think too sometimes the emotions are going to come and go. And it's going to be normal that those will fluctuate in the beginning of treatment, throughout treatment, and even after. There's all kinds of emotions that can surface within the families; and one of the things that I always encourage is open communication and really talking to each other and allowing some space.

Elissa: Yeah, we could definitely tell when we were talking to Emma, in particular, that she sounded like she definitely got emotional when she was thinking about her mom being in the hospital and not being well and being away from the family. So, yeah, that would be very difficult on the primary caregiver or just the children.

Now, are there differences and struggles with a patient who is inpatient versus outpatient, and then what about into maintenance and survivorship, like Ashlie is now?

Lynn: Yeah, I think there definitely can be those differences between inpatient and outpatient, just depending on the treatment schedule. And as we heard, using your phone, staying connected that way or Facetime. We have the technology now for families that they can use that if one of the parents is going to be within the hospital for a while and being treated there.

And then, even into, maintenance treatments or into survivorship, there are still things that are going to come up and continuing to keep communication open and talk about it. Let their family members know how they're feeling or what's happening with them.

Lizette: And some of our blood cancers are chronic in nature, like myeloma, where they tend to come back. Is that something that you see with families that have these

chronic types of cancer? Just a feeling of what's going to happen and what's the future going to look like?

Lynn: Yes. And sometimes it's the unknown, right, and really being able to know what to expect or what things to look for. But with myeloma, like you said, most often there's going to be some sort of maintenance treatment going on; and it is like a chronic condition. So, just continuing to talk about that, continuing to check in with each other. And with children, another thing is maybe getting their school involved or if the guidance counselor is available to let them know these are the things that are happening within the family.

And sometimes parents will do that and be proactive so that if issues like arise in school, then the parents and the teachers and everyone is on the same page. Some schools even have counseling or support groups for kids, so that might be a possibility for them as well.

Lizette: Right. And Ashlie spoke a lot about having family. Do you have any advice for patients who may not have that type of assistance from their extended families or friends?

Lynn: Yeah, I know that can sometimes be difficult. Families are spread out geographically now, so they may not have blood relatives nearby, but I always encourage people within their community or their neighbors or friends or anything else that they might be able to do to get connected, to provide support to themselves, as well as their children. Just to explore those options and see what they think if they have some supports and things that will be helpful.

Elissa: Yeah. Now, at LLS we have many resources for patients to get educated about their disease as well as survivorship. You've discussed this briefly, but could you go into a little bit more the resources that are available for primary caregivers and children living with a cancer patient?



Lynn: Sure, yes. So, you know, at LLS we do have wonderful caregiver workbooks and information for caregivers to be able to be there. It, it also, it provides some information for the caregivers even in taking care of themselves because we know caregiving can also be a lot.

The rules have changed so quickly and I think that's what we find with the blood cancers. It's like one moment, your family is doing all these things normally. And then the next moment, this cancer diagnosis comes along, and then everything shifts or changes. So, there's lots of things that may have changed, so we do have those caregiver resources that way.

We also have a caregiver online chat that's available. And knowing that we do have our oncology professionals who moderate those chats is so important because then you know you're going to get good, reliable information. You'll be able to meet with some other caregivers.

Another resource is our LLS patient Community, and on the communities, that's another place for caregivers to join up with other caregivers. More like a message board. And so they can send messages off, people can respond to their messages, and that might be helpful for them as well.

And then, I don't want to forget about First Connection. We have our Patti Robinson Kaufmann First Connection® program, and there's always been wonderful feedback from those that I've talked to who have used that program. They can get connected with a peer. So, caregivers can get connected with another caregiver, and then they can really discuss the things that are happening for them and maybe our LLS peer volunteers have some good ideas for that. Some things, kind of been there, done that. Not the same, exactly, but have some similar things that they can share.

Elissa: Yeah, and that's also similar, a little bit, to community that you just talked about that patients or caregivers can post a question and people can respond to that



with their own experience or, again, giving advice. So, thank you for all those resources.

Now, our final question today, Lynn, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." What would you say to families to give them hope after a parent is diagnosed with cancer?

Lynn: I would say use all your resources. Use all the information that's out there. Use your healthcare team. Ask all your questions. No question is too small. So, I really think the hope comes in communicating and talking, and asking all those questions, and getting the support that you need.

Elissa: Well, that is very good advice.

Well, thank you so much, Lynn, for joining us today. We really appreciate you discussing what it's like for families to live with a cancer diagnosis and navigate a cancer diagnosis for all different members of the family, like Ashlie and Emma. So, thank you so much for joining us today.

Lynn: You're very welcome. It was my pleasure to be here. Thank you.

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.

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In addition to the Lounge, we could use your feedback to help us continue to provide the engaging content for all people affected by cancer. We would like to ask you to complete a brief survey that can be found in the show notes or at TheBloodline.org. This is your opportunity to provide feedback and suggested topics that will help so many people.

We would also like to know about you and how we can serve you better. The survey is completely anonymous, and no identifying information will be taken. However, if you would like to contact the LLS staff, please email TheBloodline@LLS.org.

We hope this podcast helped you today. Stay tuned for more information on the resources that LLS has for you or your loved ones who have been affected by cancer.

Have you or a loved one been affected by a blood cancer? LLS has many resources available to you – financial support, peer-to-peer connection, nutritional support, and more. We encourage patients and caregivers to contact our Information Specialists at 1-800-955-4572 or go to LLS.org/PatientSupport. You can find more information on myeloma at LLS.org/Myeloma. There are also many resources for caregivers at LLS.org/Caregiver. All of these links will be found in the show notes or at TheBloodline.org.

Thank you again for listening. Be sure to subscribe to *The Bloodline* so you don't miss an episode. We look forward to having you join us next time.