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Sandy: Welcome everyone. This is Sandy Kurtin, a nurse practitioner at the University of Arizona Cancer Center, and I am very pleased today to be here with Allison, an acute leukemia patient, who will share with us her perspectives on her experience with the diagnosis, treatment, and survival with AML. So, Allison, thank you for joining us. I want to start with the first question which is, how did you feel when receiving the diagnosis? I know we saw you as a potentially benign hematology patient, but tell me how you felt when you heard the diagnosis of AML?

Allison: Yes. I was definitely blindsided, as you mentioned. We had a potential cause for my abnormal labs, so I had kind of written any potential cancer off the books, so I just felt like I'd been hit by a ton of bricks. It was something I'd never even considered, had never even mentioned it to my now-husband until a few days ago, I was like, "Oh, I'm just going to go in and run these labs. They just have to rule out cancer," and then all of a sudden we were facing this life-altering news, and my first thought, as I'm sure a lot of cancer patients is, "Oh my God, I'm dying." So, that was really stressful and scary, but I had a great team and they were really helpful in breaking the news to my family. I think that was the one of the biggest things that saved me, was that they were willing to explain to my parents and get in direct contact with them so that I didn't have to deal with that. For me, it was just okay, let's get the next step going. And, so that helped a lot, but it was blindsiding, I barely remember those first 24 to 48 hours probably, I've blocked it out of my memory, I was so overwhelmed, and it really helped that I had strong leadership and my team leader took charge. We were like "This is what we're going to do. You got to be here at this time and then this is the day that you're going to get hospitalized, and then this is what we're going to start," and I, was like, okay. Once we had a plan, I could just put my head down and get going.

Sandy: Great. Now, let's talk a little bit more, so your parents live out of town and you were then with your boyfriend, and so talk a little bit more about the communication, not having to break the news to your family yourself. Can you tell us a little bit more about that, because this was complicated, and you're a nurse, right?

Allison: Yes, I am.

Sandy: But you are not an oncology nurse. So, talk to me a little bit about that.

Allison: Yes. I have more health literacy as you mentioned than the average bear, but they don't, so it was really helpful to have you be able to explain it in a way that my parents could grasp and actually answer the questions that they had, because I was not even to the point yet where I could formulate legitimate questions about what my course of treatment was going to be, and my family had a million questions, I am sure. So, it was really helpful to have you break that down for them and answer them when I just couldn't. I had no idea what was going on.

Sandy: And I remember when we finally decided we needed to do a bone marrow biopsy and then sharing ultimately the diagnosis which came from the bone marrow biopsy, and we actually



did that by phone with your now husband. What was that like and how was it for you guys when you got together and talked about that?

Allison: The first 24 to 48 hours were horrible. I think we cried the entire time just out of fear and uncertainty of what was happening.

Sandy: Yes. Pretty overwhelming. I know we talked a little bit about how you get just plucked right out of your life, right? And you're working full-time and he's working, so what was that like, needing to talk to your employer and others about really your disruption of your life as you knew it, prior to the diagnosis?

Allison: Yes. From when the next day I walked out of the cancer center, they had told me you need to call your work and tell them you're not coming back, and so I did and somebody who wasn't my immediate boss answered the phone, and so that was really hard trying to keep my voice steady, trying not to let them know nothing serious was wrong, because I hadn't talked to my boss first, and I just told them, "Hey I'm not coming back for my next shift and I'm not coming back the shift after that," and I couldn't even talk to my boss on the phone because I was so upset and overwhelmed, I had to text her. Thank God I had her personal number, and I had to be like, "I'm sorry to do this over the phone, but I just can't pull it together, I'm not coming back because I have cancer," and those were such scary words to have to say because I'm sure like a lot of other nurses you feel like this is your passion, this is your life, it's something that gives you purpose, for me anyway, and so just to have to that ripped away and now you're on the other side, you're the patient, it was just really life-altering. I feel I carry the lessons I learned from that even today in my practice.

Sandy: Great. Right, it is very abrupt. Do you think there's anything that we as a team or any part of the team inpatient/outpatient, I mean I think that's the other piece, right, because you're really now launched into this, you're inpatient, you're outpatient, you're in and out of the clinic all the time, anything that we could've done better as a team, not just the provider team but the nurses or other staff in how we communicate, is the message consistent, what were some of your take-aways from that, and any recommendations on what we could have done better?

Allison: I loved all the nurses at the cancer center. It was nice to get to see the same faces over and over again, and you could kind of make small talk with them when you're coming in for treatment, how was your week, what are you doing this weekend, blah, blah, blah. It really made it a more calming atmosphere for me, and I was able to ask them things that I didn't feel comfortable, maybe or I thought I was over-exaggerating as opposed to calling into the cancer center when I came in for labs, I would be like, "Hey, can you take a look at this, this doesn't feel right to me," and that's how actually how they ended up finding a blood clot in my arm because I was just like "I feel like my arm feels funny, but I don't know if I'm being crazy," and then having the nurse take a second look at it, and be like, "no, it doesn't look quite right." I think if I had just been at home, I don't know if I would have reached out to anybody, but being able to see the same nurses consistently and knowing that they were friendly and knowing that they were opening to listening to me, it made it a lot easier for me to maybe pursue treatment or ask questions that I wouldn't have otherwise.

As far as what maybe could have been done better, I think they were great, but I just didn't understand, even though I do work in the medical field, I didn't understand all of the side effects

of the medications that I was going to receive, especially inpatient because it was still focused on let's get this going, let's get you your first treatment and everything, and I remember being in the hospital and having the hardest time using my phone and I just thought, "oh I'm sleep-deprived" or "oh, something's wrong," and I didn't realize it was like neurological effects from my chemo and I remember being so frustrated as to why I'm having a hard time texting, and I think if somebody told me, "you're not dumb, this is the side effects of the medication" I didn't realize there was going to be neurological side effect and I didn't realize all the side effects of steroids even though I understand steroids as a medication and we use it frequently, I didn't understand I was going to get violent mood swings or be up cleaning my house all night because I couldn't sleep after getting steroids, so I think just being upfront about "this medicine might make you crazy," would've been helpful.

Sandy: Great. So, really important is there's so much information that you get in such a short period of time. It's so overwhelming even for someone with medical knowledge that you can imagine what it's like for someone who has no knowledge, it is overwhelming and so we do need to try to figure out a way to parse that out in a way and reinforce it as you go forward to your point, so that's really great feedback. So, you mentioned the neurotoxicity that comes with high-dose AraC or cytarabine, and then you had a blood clot from having the line in your arm. What are some of the other challenging side effects that you had and tell us how they affected you?

Allison: I feel like I actually ended up running the gamut of a bunch of things I never thought I was going to personally experience through this experience. At one point, my PICC line got infected and I got MRSA bacteremia and had to be hospitalized, and that was mind-blowing. I tend to be one to brush off symptoms unless I feel like they get really serious. In hindsight now I realize that I have no concept of what is really serious and what is not. There were so many things I could've missed if I did not have my doctor and these nurses all watching out for me and pointing things out that are not normal, but that was really scary too, to realize how sick I had let myself get without realizing that there were the problems.

Sandy: Right, that was just maybe a little pimple and it turned out to be more than that, right. So, how long did it take you to start to feel like yourself?

Allison: After treatment was completely done, I did kind of cheat on my last treatment. We stopped mine early because my bone marrow was not quite recovering and they gave me Neulasta (pegfilgrastim), which was a game-changer. So, that helped a lot on that last round and I don't feel like it ran me down as much and they gave me less chemo on the last round too. So, I feel like I had an easier road, but that second dose was horrible, and that's the one where I ended up having MRSA bacteremia and a lot of other complications, but from my last chemo treatment I would say it was a good four months before I stopped feeling like I was dying every time I did any sort of work or activity or anything, and now about six months out I think I'm, or now I guess it's way longer than that, but I feel like I'm about as close to my baseline as I expect to get now.

Sandy: And in all fairness you were incredibly fit, an athlete and young, so, again, we imagine what that might be like for somebody who is older or who is not fit or have comorbidities, so even with someone like you who is otherwise young and healthy, a very challenging process for sure. Anything else you want to share about what other opportunities, or what would your message be

to nurses as they work with these patients and what can we all do better in helping people through this journey and through the recovery period?

Allison: I would say going into it, I mean, and the nurses that I met at the cancer center were really great in that they were really good at meeting me kind of where I was, like if I had one question they took the time to answer it, if I didn't really want to talk and just want to be left alone with my Kindle that day they were cool with that, too. They were really helpful and they were really good at explaining things before we were going to do it, so I had an idea of what my treatment plan was and what was going to happen next, and I felt like there was really good communication throughout the whole cancer center which was really helpful, and if I had a question they could just call my doctor's office which was right there and get it clarified. I also think some of the resources they gave me were helpful, but I also found some more helpful resources probably a little later after I had missed it. I did not realize maybe how helpful social media could be. I didn't really have anybody else's experience to go off of, and so I think it would be helpful maybe to find some other, I found an Instagram account about cancer patients and their experiences, and it has really helped me realize that, "oh these things that I'm feeling or the things that I'm seeing is normal," or "this isn't normal," and educating myself on the Leukemia & Lymphoma Society has been really, really helpful, but I think in another sense I didn't ask enough questions or I didn't want to do a lot of research on my own when I was in it because I didn't want to be stressed out about potential things that could happen that were not happening to me, if that makes sense. To this day I don't look at what the numbers are for survival after AML with just chemo, which is what I did, or what the relapse rates are and stuff because I don't want to freak myself out any more than I already can be because I think when you're in it you're either worried about something that's happening to you or you are worried about what could potentially happen to you or if you're going to get bad news next.

Sandy: That's the reality, right? And so, you're a survivor and that's I think very fitting for someone who has had any kind of cancer diagnosis, that's always part of what is in the back of your mind and choosing to focus on being well and being in the moment is a great message, and a message for us as clinicians to help people focus on their living and being well, and all of that, so I think that's a really great way to sum it up. It is a difficult journey for anybody and AML is very abrupt. It does not give us a lot of time to think or ponder or discuss. It's something that needs to be dealt with very quickly and so that makes it very challenging, certainly for you and for patients, and you were able to finally get married, right? Which was great, albeit a slightly different plan, right?

Allison: That's okay.

Sandy: But we were very happy about that. Anything else that you want to share with the nurses that will be watching this series that you think is important?

Allison: Just keep doing what I know you guys are doing, I know you guys advocate for your patients, I know you guys listen to us, and that honestly, like I said, meant so much to me because it really was my nurses who caught some of the symptoms as problems or noticed that there were problems with me before I even noticed. Actually two days before I was hospitalized for the MRSA bacteremia, I came in to just get... Oh, I had gotten a really bad bloody nose and they wanted to draw labs, and my nurse was like, "You don't look right. Are you okay? You don't look like right," and I said, "I'm okay, I'm okay." And then a two days later I come to find out I've got MRSA bacteremia, and I feel like she picked up on it two days before I even had an idea that anything



was wrong, or like I said the blood clot, so just keep listening to your gut, and listening to your patients, and just talking to us. I feel like that a couple of times really saved me or really contributed to me getting an intervention that I needed in time just because the nurses were looking out for me and the team was looking out for me.

Sandy: That's a very good point, because in between provider visits the nurses are really the safety net, aren't they, because you are in frequently for labs, you may not be seeing one of the providers, and so that is really a key message, and that continuity is really important so that people that know you say, you know what, you just don't look like you did yesterday or the day before, so really a great message there. Some of these are really subtle and they may present in an unusual way. So, a really good message there. Okay, I think we are at time, and so thank you so much for taking the time to share your story. I think it's really important that we hear from someone who has had the experience and take that to heart, and we can always do better and social media is definitely something that is critical for not just younger patients but everybody, particularly now, and so that's a really good message as well, and I think with that we will thank you again, and I hope you have a wonderful day.

Allison: I appreciate all the work you guys all do, you literally are saving lives and I appreciate the work everybody did to save mine.