THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'A Conversation with Caregivers'

Description:

To kick off Caregiver Awareness Month, we invite you to join the conversation as we chat with three caregivers! Listen in as Alicia and Lizette speak with Mirinda, David and Alejandro about their varying caregiving roles. Mirinda, David and Alejandro will share how their loved ones' acute myeloid leukemia (AML) diagnosis impacted their own lives. On this episode, they describe the changes they went through, where they found support, how they navigated insurance, what they learned about themselves and helpful advice for other caregivers.

Transcript:

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

Lizette: And I'm Lizette. Thanks for joining us today.

Alicia: Today we'll be speaking with three caregivers – Mirinda, David, and-

Alejandro: Alejandro.

Alicia: - about their caregiving experience. And we'll just be talking more about their journey, when the patient was diagnosed and how that experience was.

We'll start with Mirinda, tell us about who it is that you were caregiving for. You can just use their first name, their diagnosis, when that was, what was going on around that time. And we'll go around the room.

Mirinda: Kevin, it's my husband. He was diagnosed April 8 of this year. Uh, very quick onset. He was just sick one morning, didn't go to work. That evening when I got done with work, he said, "Take me to the hospital."

Alicia: Hmm.

Mirinda: That was a Monday. By Wednesday, we were in the hospital at Ball Memorial in, over by Indianapolis-

Alicia: Um-hmm.

Mirinda: -and by Friday, he was at the VA hospital in Indianapolis. And by Saturday they were doing chemo.

Lizette: Oh, wow.

Mirinda: So it was that quick of a diagnosis and onset.

Alicia: Um-hmm. And now was he the type of person that held off from going to the hospital or the doctor if something was wrong?

Mirinda: Yes.

Alicia: Well, uh, so you knew-

Mirinda: He's, he's not ever really been sick.

Alicia: Yeah.

Mirinda: It's the first time he's ever been in the hospital-

Alicia: Um-hmm.

Mirinda: -was when he was in the Navy, and he ended up with chicken pox.

Alicia: Oh.

Lizette: Oh.

Mirinda: So that was '80, '81.

Alicia: Oh, wow.

Lizette: Yeah.

Mirinda: He's never been in the hospital.

Lizette: Wow.

Mirinda: So, no, he didn't get sick.

Alicia: Yeah, because we hear so many stories. A lot of people will say, "Oh, like I felt something, but I didn't, you know, I just decided to wait it out."

Mirinda: He was nauseous.

Alicia: Yeah.

Mirinda: Dizzy and we just thought it was the flu.

Alicia: Yeah.

Mirinda: So, yeah, quick onset.

Alicia: Wow, that's very quick.

Mirinda: Yeah.

Lizette: And his diagnosis is?

Mirinda: Acute myeloid leukemia. He ended up with that.

Alicia: Thank you for sharing.

Lizette: Yeah. Alejandro?

Alejandro: Oh.

Alicia: You're up.

Alejandro: Oh, it was, uh, my brother; Alonso, he uh, got diagnosed in December 2016.

Lizette: Um-hmm.

Alejandro: And then he had treatment, got it cleared up, and it came back November 2018. Almost a year. He was a couple, like two weeks away from the year.

Lizette: Wow.

Alicia: Hmm.

Alejandro: And, then he got the transplant on, uh, February of this year.

Alicia: Um-hmm.

Alejandro: When he got it, it was a, he went for a week to a convention where he worked at in Bastrop. It's like an hour from Austin and, he came back. He was tired. That was like the first symptom. He was just tired, kind of weak. And after that he got thrush. Uh, you know, what babies get.

Lizette: Yeah.

Alejandro: Sores in the mouth and such.

Alicia: Um-hmm.

Alejandro: And so he went to the doctor, and the doctor was like, "Eh, that's kind of weird." But she gave him antifungal medicine. I think it was like a week later he started getting a fever. It was just persistent fever. It wouldn't go away. And that lasted for a few days.

And then, my mom tried some home remedies for fevers that usually work; and she's like, "No, something's wrong." So then they took him to the hospital, and the hospital did like blood work and, sent him on his way. they gave him some stuff to control the fever; and then like two, three days later they called back and told him, "You've got to come back immediately."

Alicia: Yeah.

Alejandro: And he was in there for a month. Then they find out this was AML.

Alicia: Wow.

Alejandro: And then he got treatment like a week later, started chemo.

Alicia: Yeah. Dave?

David: Uh, you know, the, my wife presented with, uh, a fever for an extended period of time, so similar to, to your brother. And, uh, after probably five or six weeks, she just went in, uh, saw a doc. They ran some tests. Her white blood count was very low. And, uh, so low that, uh, this would have been, uh, November for 2004. And as a family, we generally do the Turkey Trot or 5K in the area.

Alicia: Wow, yes.

David: And, uh, they advised her to not even do that, which was kind of freaky, to say the least.

Alicia: Um-hmm.

David: And, uh, eventually, after blood tests were run and everything, uh, it came back that, uh, that she, uh, had AML. Uh, and almost embarrassingly, uh, when they were transporting her from the first floor where they had done a bunch of tests we got off and my wife said, "Did you see where we are?" I said, "Yeah, we're on the fourth floor." So I'm the idiot. She says, "No, that says Oncology.

Alicia: Umm.

David: And that's, uh, that was our first indication that something was really wrong.

Alicia: Yeah.

David: And then when they, when they completed the tests later, uh, and I think even the next day is when we got the results. So it was, uh, it was, uh, it was a shock.

Lizette: Yeah.

David: So, uh, but this was, uh, like I say, back in 2004. Then on March 31, 2005, she had her first transplant. And then her marrow kind of stopped working. It wasn't, uh, she had to have infusions all the time. Essentially the marrow wasn't making blood, so she had a second, uh, transplant November 27 of 2007. And she's been in remission actually since the first one, but, uh, as normal as we can get since that second transplant, so-

Alicia: Right, right.

David: -pretty fortunate.

Alicia: Yeah.

David: It's been an extended period.

Alejandro: Oh, your, your wife, she actually had low counts? Uh, the white blood cells were low?

David: Uh.

Alejandro: My, my brother was, his were like through the roof, insanely high, white blood cells.

David: Oh, that's right. Yeah, is the platelet count that would have been done, Alejandro? I'm trying to remember.

Lizette: Platelets.

David: Yeah, the platelets.

Alejandro: Oh, okay.

David: I meant that, you know.

Alejandro: I was just curious.

David: Yeah, that, that seems right because of the infection and, and, yeah.

Alicia: Right, right.

Alejandro: Because when my brother relapsed, his, uh, he had no symptoms, which was weird. He felt fine, but, um, the counts were just steadily going up.

Alicia: Oh.

Alejandro: Uh, so I was just curious. Wow, that's interesting.

Mirinda: Kevin's was low.

David: Yeah, I, I don't think it was the platelets. It was more white blood cells.

Mirinda: His white count was like 17. And when we got diagnosed, he was down to 6.

David: Yeah, because I remember hers were down to 30, and that just meant she had no ability to fight the infection is what it was. And-

Alicia: Oh.

David: So, yeah.

Lizette: So it's two extremes. It could go high. It can go low.

David: Yeah, that's interesting, interesting.

Lizette: So did you guys know about leukemia before?

David: Nothing, yeah.

Alejandro: Yeah, nothing.

David: You know, my experience was that was a childhood disease and that, you know, the only time I'd really heard about it is people that are dealing with their children had died. And, and so it was, it, it just turned into a whole new world. And then we got an education that you never expected to have.

Alicia: Um-hmm.

David: So.

Mirinda: I've dealt with other cancer. My first husband passed away. He had bone cancer that got into his lungs.

Alicia: Wow.

Mirinda: And they went in three different times and took parts of his lung out. Both sides of the lungs out. And he passed away, and so I dealt with that type of cancer. We didn't do chemo or anything because it wouldn't have done any good. And then to do this with a totally different, different thing.

Alicia: Right.

David: Yeah.

Mirinda: And so it's just, uh, a completely different concept.

Alicia: Right, because now you're a caregiver, again, to a spouse.

Mirinda: Yeah, and, of course, my first thought was why again?

Alicia: Yeah.

Lizette: Um-hmm, yeah.

Mirinda: It's hard.

David: Yeah, I had a similar experience because my dad had, uh, maybe 25, 30 years before he died, he had bladder cancer. And it was eradicated for like 30, 35 years. And then it came back, and he was literally in, in his final days when Rona had her, uh, transplant.

Alicia: Um.

David: So, yeah. And she shouldn't have been driving probably, but she drove our two daughters down for that funeral, basically. So, uh, when we came back with him, that, you know, the doc basically said that, you know, the cat is out of the barn. I was like, "That's probably not the best way to, to put it, but."

Alicia: Yeah, bedside manners.

David: Yeah, so it was, it was a tough thing to take; and it was.

Alicia: Yeah.

David: And we were already kind of running on empty.

Alicia: Yeah.

David: Quite frankly. And then just to be experiencing that at the same time was pretty, pretty challenging.

Alicia: Yeah. We were talking to one, another patient and she was saying that her father was diagnosed with kidney cancer and ended up passing away. And so that was the family's first interaction with cancer.

So when she was diagnosed with lymphoma, years later, their automatic mindset was, "Oh gosh, again, the same thing's going to happen." And she said that it was her job to kind of do the research for them to let them know that having a cancer diagnosis doesn't necessarily mean that it's going to be the same outcome for everybody.

David: Right.

Alicia: Yeah, yeah. So you mentioned it was your brother. Is that the only sibling you have?

Alejandro: I've got, uh, two brothers. There was three of us altogether.

Alicia: Yeah. And you mentioned this was the first time you came in contact with leukemia, right, for all of you.

Mirinda: Um-hmm.

Alicia: Where did you, had you known about the Leukemia & Lymphoma Society? Had you seen or heard or read anything about them?

Alejandro: I've seen, I've seen, yeah, I've seen logos and such.

Alicia: Prior to?

Alejandro: Yeah.

Mirinda: Yeah, I had too. Yeah, I mean you see that stuff on commercials on TV; but, and, I mean, I know it was a blood cancer, but never the extent of exactly what is involved.

Alicia: Right and how complex it is.

Alejandro: Yeah, I didn't even know it was cancer. I thought it was a bl-, a blood disorder.

Alicia: Yeah, I know a lot of people, actually, that's common.

David: I don't think I had exposure to LLS before, and let's say this is, you know, 13, 14 years ago. So, uh, but we've had a lot of exposure since.

Alicia: Yeah, unfortunately.

Lizette: So where did you get your information about leukemia?

David: Mostly from the docs in the hospital, to be honest. I think it just took us by, so much by surprise that we, we just- I didn't even know where to go, to be honest with you. Uh, they did have kind of a, a program at the hospital and they'd kind of walk you through stuff. So, transplant and, and they did have concerns about, you know, the caregivers and, and things to, you know, how to take care of yourself and make sure that you did.

But it kind of stopped after that, that, you know, afterwards. Uh, they did have a few folks on site, but they were mostly patient-focused and not really caregiver-focused at all. So, at least that was my experience.

Mirinda: Social worker told us about the website, that we definitely needed to go check out the website because there was tons of information and the caretaker part on there and the patient part. So that's, haven't really got on there yet to go explore, but-

Lizette: Did the treatment team, like David's hospital tell you about the caregiver, taking care of yourself?

Mirinda: Yeah. The, uh, social worker did. They come up and say, well the nurse sat with me when I would go visit and stuff with him.

Lizette: That's good to know because a lot of times we have been hearing from caregivers, and that's not their experience. Um, everybody's asking about the patient, your loved one, and nobody's really asking about you. And we talked to a caregiver that was years into treatment for their loved one, and somebody, um, just said to them, "How are you doing today?" And they were just so shook up with emotion, I think they cried because nobody had asked them about themselves.

Mirinda: Uh, we were very fortunate. I'm very impressed with the VA hospital because I've never dealt with. I've always heard bad stories about VA hospitals and stuff. But, um, found out that Indiana University was also involved with the VA, so they worked together, which they're a teaching hospital.

And I can't say enough about the nurses that we had because they actually did, when I, I would go up on the weekends, because I'd stay home and work all week. And then I'd go up on a Friday and stay all weekend. And they would come in and ask me if I needed anything, if I was okay.

We go up to that floor to see what nurses are up there working that day to go visit and let them see his progress because they don't get that very often because most patients don't go back. And they don't want to go visit. You know, but we go visit our nurses.

Alicia: Oh, that's nice.

Lizette: Nice.

Mirinda: So they help a lot.

Alicia: Yeah.

Mirinda: And we were concerned about whoever was there with him if they needed anything. So that helps if you have a good nurse, nursing staff.

Lizette: It does. And you're the spouses. How about you, Alejandro? Did they speak to you as a caregiver? You're a sibling.

Alejandro: Yeah, yeah, they did. Usually they're just, "How are you?" "Good. I'm good." They were telling me again all, you can't get sick and this and that. You know, that sort of stuff. Don't get sick. Uh, wash your hands and, uh, use Lysol. well, I use

Lysol a lot. I just think that, if I thought there was like, here, that guy, if I thought that guy sneezed and didn't put his hand there, spray Lysol all around. Um, yeah.

David: That's, that's interesting. Like for me, when Rona's going to come home after the first set of chemo, uh, really just kind of the induction stuff before she got moved to a different hospital, they told me, "You need to clean the house down." And I, I got containers of Lysol wipes.

Alicia: Um-hmm.

David: And as far as I could reach, every wall of the house, I mean I was cleaning like a mad dog. And I was, and I, I remember it, you know, just being alone that night and, and it was like, I was just exhausted. I was out of gas. But it was like we had to do it.

But, you know, I, I don't want to change subjects, but one thing I learned after my wife's experience and really our experience, is just awareness of other people with different cancers and stuff. Part of my job is overseeing HR at our little charter school, and, uh, well, you know, I knew people that were both caregivers and, actually, undergoing treatment. And, you know, with those undergoing treatment, I always told them, "Stay out of the pain." And those that were caregivers, I always tell them, "Take care of yourself."

Alicia: Um-hmm.

David: Because if you don't take care of yourself, you can't help anybody else.

Alicia: Yeah, and that's so important to mention because I remember when we were talking to, I believe it was a social worker, and she was saying that just like how on the airplane, you have to put a mask on yourself first before you can help the person next to you, it's understanding that as a caregiver, like you said, taking care of yourself so that you can properly take care of whoever it is. Yeah.

David: But it's hard to do because when you first start, you're like Superman. You, you just, I mean the adrenaline or whatever, things start pumping and, and it, it's amazing how quickly you can crash too. And, I mean, I, I, I could remember sometimes I just felt like walking into the closet and crying.

Alicia: Yeah, yeah. Well, on that same point, uh, what did you do to intentionally incorporate care or self-care for you guys because, you know, Lizette mentioned earlier and studies show that the impact of cancer, of a cancer diagnosis can be just as bad or just as stressful or, on a caregiver as it is for the patient. So how did you guys intentionally just incorporate self-care?

<u>David</u>: I can't give you any real good examples. I think part of what helped keep me going is, you know, 60 miles away I had a daughter in college; and I still had a high school student, a 10th grader at home. And I guess from in sense of the diversion of trying to take care of them kind of took me away from, uh, the whole AML situation. But, uh, I mean it was, it was just a challenge.

<u>Lizette</u>: Yeah.

<u>David</u>: Yeah, I tried to stay, uh. We live 60 miles from the hospital, and I'd try and stay at, in, at the hospital with her evenings and sometimes at nights, but not very often.

<u>Alicia</u>: Um-hmm.

<u>David</u>: So, uh, we were fortunate to have friends that took my daughter in who's still at home.

<u>Alicia</u>: Ah.

<u>David</u>: And, and she would sometimes spend two or three nights in a row with them. And, and so just really lucky that I had some good friends. Uh, but, I know, it was such a crazy time.

<u>Alicia</u>: Um-hmm.

<u>David</u>: I mean because you know, I was fortunate. I was in banking back then, and, uh, they, uh, you know, really the president of the bank, uh, who I would call a friend, uh, said, "Just do what you need to do, and then get out of here." So I had the advantage of not having to work, you know, clocking for eight hours. I mean some days I'd be in there for two hours. Sometimes half an hour, and it's, you know, that's what I needed to do; and then I'd be gone.

And I never got docked or nobody counted my hours. Uh, so, I don't know, I, I, I just felt like I was pretty fortunate to be in the situation I was considering everything else that was going on.

<u>Alicia</u>: Yeah.

Mirinda: I have that right now too with that because I work from home. So, my supervisor's been, when I send a message or someone, doc's coming or even when it happened, take whatever you need. We can't stay constant with them-

Alicia: Hmm.

Mirinda: -because then we can't take care of ourselves because we are constantly looking at them, watching them breath. Um.

David: Oh, yeah.

Mirinda: And if you're there constantly, then we fall apart; so we're not strong enough for them. So that's why I stay home and worked all week and only went to the weekend to be with him because if I was there constantly, I wouldn't have been any good.

David: There is that of you that you have to-

Mirinda: Well, yeah, you have to shut down partway because-

David: Right.

Mirinda: Uh, you get too in-, you have to be involved. But if you get, immerse yourself in with them, then-

David: And that's a hard thing to admit, actually.

Mirinda: Where you, I know. Where you draw, well, you have to draw that line.

David: For yourself.

Mirinda: Yeah, we do.

David: And then-

Mirinda: Or we're going to get sick, and then what, we can't do any good for them.

Alicia: Um-hmm.

Mirinda: So, because I had that issue with my first husband. I went back to work after he passed away after two weeks. And people say, "Why?" I said because if I don't, I will stay home, and I will go crazy because all you do is sit there and think about things. And you have to involve yourself in other things to, at least to keep yourself sane.

Mirinda: So that's another way to take care of ourselves.

Alicia: we've heard that from so many caregivers where it's a matter of like I don't know if I should say it. But it's true.

Mirinda: I know.

David: Absolutely.

Alicia: In order for you to take care of yourself.

Lizette: And not feel guilty about it.

Alicia: Um-hmm, yeah.

Lizette: Because you have to-

Mirinda: Well, you do a little bit.

Alicia: Yeah?

Mirinda: You do feel guilty a little bit.

David: Yeah.

Alicia: There was one lady we were talking to and she was a caregiver of her husband, and she was saying that it may sound small to somebody, but she said the most helpful thing for her was her friend calling her and saying like, every week, "Let's get our nails done. Let's go to the movies." And even though it sounds super small or it, or someone might say, "Oh, that's it?" But for her, she was like, "I felt so guilty knowing that, God forbid, something happened, I was getting my nails done." But she needed that time. She needed to at least do something that had nothing to do with the diagnosis.

Mirinda: Right.

Alicia: So she felt like she was taking care of herself.

David: So, Alejandro, if you come to Denver, I'll take you to get your nails done.

Alejandro: I think I'd like that. Thank you.

Alicia: So how was it for you, Alejandro?

Alejandro: What was the question again?

Alicia: What did you, oh, yeah, how did you intentionally incorporate self-care.

David: But you, you worked a lot of hours though.

Alejandro: I worked a lot.

Alicia: Yeah?

Alejandro: I worked a lot for, you know, like a couple of, since 20-, since 2016. So like two years, I worked almost seven days a week.

Alicia: Wow.

Alejandro: So my dad could, uh, stay with him.

Alicia: Yeah, yeah.

Mirinda: Now did your mom stay with him a lot too?

Alejandro: Well she can't drive, so if my dad can't drive or my dad had to drive her around, but he also had to work. So I'm like, "Well, shoot, dad, just quit, and I'll pay you."

Alicia: Wow.

David: Yeah, he stepped up so his dad could spend more time. There are so many amazing stories with this. To me it's really an amazing story.

Alicia: It really is. And to show the sacrifice that people have to make to make sure that things are taken care of, yeah.

Alejandro: Yeah, it was hard.

Alicia: Um-hmm.

Alejandro: I don't think I need a tissue though.

Lizette: I do.

Alejandro: So, yeah, I mean I worked a lot.

Alicia: Um-hmm.

Alejandro: I repair machinery, so I get dirty all the time. So I'd be like, "Well, bro, I ain't going to be able to make it because I got, I was welding, so I got welding fume all over me."

Alicia: Um.

Alejandro: I read. I don't know how true it is, but I was like, "Eh, better safe than sorry." So, apparently, when you weld, you get micro metal, mic, now what is it? Nano? Nanoparticles, micro particles. I don't know. They're tiny particles of metal. And I go, "That can't be good to breath." So I just won't go there if I, I get like dirty with matrix; and the doctor would say, "Ah, don't," uh, what would he say? If they were cutting grass or if you got grass clippings on there. Fungus and stuff growing in there. "So you don't want to bring that in." So I'd be like, "Oh, I ain't going to make it, bro. I have to go another day."

So, but my dad was there, so it's okay. He was there. My mom was there. They'd keep him company.

Alicia: How is it as a caregiver navigating something as complex as health insurance and figuring out well what was available to you as a family? To the patient?

Mirinda: Well we have the, we go strictly through VA. He has nothing else because he has just started a new job the first year, and it was a small company. So under 50 employees, so he would have eventually got insurance, but he hadn't been there long enough yet. So all we have is strictly through the VA. So, and that's, I don't know if we didn't have that – then it would be very difficult.

Alejandro: Yeah, my brother had good insurance. Well, not good insurance, but he had decent insurance. So a lot of the premium was paid. It was okay. They covered most of it, and, uh, I don't know about the copay. I'm not going to ask him about the copay.

Alicia: As far as you know, it was.

Alejandro: Yeah, as far as I know, the, the, most of it was paid for by the insurance.

Alicia: Yeah. We did an episode this morning actually with, her name's Monica Bryant. She's a cancer rights attorney, and have you ever heard of triage cancer? So Triage Cancer is this nonprofit organization that is kind of in line with us in that they provide a lot of resources; legal advice; and just, practical resources and education for patients and caregivers.

And they have so many things on their website that talk about how to address employment issues or how to even like budget yourself or health insurance-related topics or concerns.

And she was just talking about, how insurance is such a technical world that now the person has to experience in the capacity of a caregiver or a patient.

How is it for you, David, navigating that world?

David: You know, we were pretty fortunate and, quite frankly, Rona takes care of our finances. I'm an accountant by trade, but she takes care of everything. So, literally, we just kind of hung in there until she got to about 30%, and then she dealt with it when that was, and that was her area.

Alicia: Yeah.

David: We just, uh, you know, it was good insurance, first of all, to start with. So, I mean, we had small deductibles, small out of pocket. So everything was handled pretty well. But, you know, uh, you start getting notices like three or four times a week and you get to see every bill; and I, the, the largest single one that I remember was well over $200,000. And you look at that, and you think of people who don't have insurance or have crappy insurance. And you understand why they go bankrupt. I mean I can't even imagine. If we didn't have that insurance, we, we could just kiss everything that we have today goodbye; and, and it's not about material goods. But we would have to declare bankruptcy. And, and it, we would just, there wouldn't have been a chance.

And I do feel sad when I think of people like say that have the bad insurance programs or no insurance at all. And, you know, generally those people don't have the means to even seek assistance or don't, aren't aware of it.

Alejandro: And you just get kind of double-screwed, you know, and just, uh, it's, it's a sad reflection on, on the US in general, to be honest with you.

David: But the means that same people go, you know, what they do to try and make it work for them. You know, because most people when you come down to it, most people are good at heart. And, and they only want to do the right thing.

Alicia: Everyone deserves to live.

David: Right, so.

Alicia: So what did this experience teach you about yourselves because, again, I, I know the question's always, "How's the patient? What did the patient experience? How did it affect you?" But what did you guys learn about yourselves during this entire-

David: That's a-

Alicia: -new role of caregiving.

David: That's a great question. I don't even know if it's a fair question.

Alicia: It's not.

David: I mean we've been several years out.

Alicia: Um-hmm.

David: The awareness was the big change for me. I, I think, am I a better person for it? Probably not. Uh, but I'm more aware so it might seem like that I'm a better person. And, uh, so I mean just the part where I, like I mentioned before, I, I've been able to reach out to other people without the awareness, without going through this experience, I probably would have felt bad for them; but would not have thought of doing some of the things that I do.

Lizette: That's empathy. Yeah, yeah, yeah, definitely.

David: Well perhaps I owe you, I gained more in empathy then.

Lizette: It's hard to step into somebody else's shoes if you don't even know-

David: That's true.

Lizette: -what they're going through.

Alicia: Um-hmm.

Alejandro: What was the question? Did I learn by myself?

Alicia: What did you learn about yourself?

Lizette: You're a hard worker.

Alicia: I know, we learned it. We learned that.

Alejandro: Yeah. You know what, I was lazy prior to that. I used to work part time prior to all that going.

Alicia: Wow, so you went from part-time to seven days a week?

Lizette: Wow.

Alejandro: Yeah, I was lazy. I was like, "I don't have the time."

Mirinda: You learned how much strength you had.

Alicia: Exactly.

Alejandro: I, uh, yeah, I didn't like, I don't, oh, I, okay, so I don't really like working. If I had-

David: Amen brother. You know, I-

Alejandro: I really like. I, I really, I took that one, yeah, good. I, I like working part time.

Alicia: Um-hmm.

Alejandro: I'd leave earlier. Yeah, I'd leave earlier. And, uh I like to just hang around. And after that I was, oh, man, I worked a lot. Uh, sometimes I'd come home at midnight do it again the next day. So, uh, yeah, I guess maybe that, if I could, I could do it.

David: It sounds to me like you really learned the value of family. I mean you-

Alejandro: Oh, no, I think, I always had the-

David: Yeah, I know, but you, then you just like expounded on it because then you were the one that- you, financially, you have to take care of your family, you know?

Alejandro: Oh, yeah.

David: So, I mean, your brother didn't work, you basically told your dad to stop working, and you, you told your entire family you're going to take care of things, right?

Alicia: Um-hmm.

Alejandro: I did. I didn't tell them I was-

David: You just did.

Alicia: Yeah.

Alejandro: Yeah.

David: I mean you don't have to tell them specifically, but if you, if that's what happened, you told them in one way or another that you're going to make sure everything's okay. So I totally respect that. I don't-

Alicia: Oh, absolutely. Absolutely.

Alejandro: Yeah, I guess that, okay. I'll take that. I'll take that. That sounds good.

Mirinda: You are a very good man.

Alejandro: That guy's single too.

Mirinda: I was just getting ready to say something like that.

Alicia: Oh, my god, that is so funny.

Alejandro: Yeah, they should come to Texas.

Mirinda: Elgin, Elgin, Texas. Right outside of Elgin.

Alicia: If we have any Elgin, Texas, listeners, comment below. Comment below.

Alejandro: They, they have a really good opportunity.

David: Hey, Rona, that's, that's Alejandro speaking, not me, all right? I just want to be clear on that.

Alicia: and what about you, Mirinda?

Mirinda: Oh, I don't know.

David: Oh, wait a minute. This is a podcast, and so it's not video.

Alicia: Um-hmm.

David: He, he is a good-looking guy.

Mirinda: Yeah, yeah, he is.

Lizette: And you're a caregiver twice over, so.

Alicia: That's also strength.

Lizette: Yes.

Alejandro: Yeah, you're tough. Just keep that toughness.

Mirinda: Had to be. I have two boys too, so. I've got to learn how to tell my husband that he can't do things though, it's been fun. He thinks he's able enough to go driving like he used to; and right after he got out of the hospital, he thought he was able to drive to go see the, his bosses. He was going to drive by himself. I sent my son, uh, my son with him because he, you know, they get to that point. So, yeah, I've had fun about telling him he can't drive.

But I mean it's not his fun, but I mean you've got, you've got to be strong with them though, sometimes to the point that they think they can still do things; and there's times that they can't.

Lizette: Yeah. Well it's hard. You have to start-

Mirinda: Relearn, yeah. Well you relearn, yeah.

Lizette: -you know, and reeducating about what you can do, you cannot do and how much time you need to be able to do it again.

Mirinda: Yeah.

Lizette: You know, it's, it's-

Mirinda: That's a process.

Lizette: It's a lot. I mean a lot of you have gone through, um, you know, your loved ones have gone through a transplant-

Mirinda: Mine hasn't yet

Lizette: -which is, um, you know, even harder at post-transplant. And one thing that I, I really, um, want to acknowledge is that everybody on the street knows that, um, sometimes we're more a danger to the patient than they are to us. Everybody thinks that, oh, you know, that person has leukemia. You know, we can't get leukemia from anybody; but they can get a cold from us-

David: Yep.

Lizette: -easily. Um, more so than, that we can get a cold from them.

David: And you're more susceptible to stuff that, if you let yourself wear down, so-

Mirinda: Yeah.

David: And you've just got to be careful.

Alicia: So for the caregiver listening, what advice would you have for them?

David: Still the same. Take care of yourself. Do what you can to break away and do things for yourself and make sure you get lots of rest, and. And have some, check, check in with somebody. Just say, you know, how do you think I'm doing? You know, ask, make somebody pay attention to you that's not part of a hospital situation.

David: Just get, get someone to check in with.

Alicia: Yeah, that's a good point.

Mirinda: Yeah, family, friends.

David: Yeah.

Mirinda: Yeah, know and call your, yeah.

Alicia: Yeah.

Mirinda: Because that definitely helps. I, my cousin doesn't live too far; and she would at least come once, twice a week just to sit and, you know, chat and see how everything was going. She, uh, if everybody has somewhat of a support team behind them, the caretakers too, I mean the patients definitely; but caretakers need support, also.

Alicia: Um-hmm.

Mirinda: So family and friends to help out.

David: Be strong.

Mirinda: Makes a difference.

Alicia: Be strong.

David: Be strong, yeah.

Alejandro: That's probably it. Like-

Alicia: Um-hmm.

Alejandro: Uh, 'cause the patient could have lows and you have to try to be strong for them.

David: Right, absolutely.

Alicia: Yeah.

Mirinda: Yeah, when they get aggravated and really easy; so you've got to work through that too.

Alejandro: You're right. even if it's the hardest thing you've done for a long time, you've got to be strong for them. Even if when you leave the room you collapse. It's just-

Mirinda: when you leave then, then you can cry.

Alejandro: Yup, yup.

Mirinda: Or, you know, sometimes if you have the right person, you can cry together though too

Alejandro: That's true.

Mirinda: Yes, that's good too because me and Kevin have, we've done that. We've cried together over this.

Alicia: Um-hmm.

Mirinda: And that actually has helped a whole lot._Yeah. Because a lot of people can't, I don't know how you and your wife are, but there's probably a lot of spouses, you know, husband and wives that don't cry together.

Alicia: Yeah.

Mirinda: So if you can, that would be really good. Is to share that part with each other. Even with your brother too. You, again, have to be spouses and-

Alicia: Yeah.

Alejandro: Well, we don't really, we weren't that- I mean, that's my dad's fault. That's my dad's fault because, because we-

Mirinda: You don't show emotion then is what you're saying.

Alejandro: Yeah, not too much. But by this time, this time, yes, like-

Mirinda: It helps. It helps, I think.

Alejandro: Yeah. No-

David: Maybe it just comes down to mirroring whoever you're with in some situations.

Lizette: Yeah.

David: Like my wife, Rona, she's just, she's just a tough New Yorker; and she's never let on to be anything other than that. And that was before and now, and it's after AML. So, yeah, she can drive the bus.

Alejandro: Yeah, because we see it is there's no point sulking about it. You've got it, and you have to get through it. So, yep, just-

Mirinda: Yeah.

Alejandro: Grab, I guess grab the bull by the horns and get it done.

David: Yeah.

Mirinda: Yeah.

Alejandro: And that's, I mean that's the only choice you have or well, well, it's not the only choice you have, but that is the best choice.

Alicia: Yeah, yeah.

David: Because Rona was like, you know, they, they gave us some funny options at the beginning, saying, well, well I didn't even know if they were options. I had known someone who's spouse had survived after just chemo and had been in remission. And I said, "Well what if-"You know, I'm like, "Well maybe we should think about considering this to see how it works out." And she's like, "No." It's all or nothing.

Alicia: Um.

David: With, with her. I mean she's like, "We're, we're shooting for the cure as soon as we can. We're not going to, going to let this play out and see if it does or doesn't work.

And it was interesting. Uh, the first time we had a serious talk with the oncologist, I think it was now we're meeting; and then he listed, you know, chemo and like three or four times during that initial meeting, "After this part, you could die. And after this, you could die. After this, you could die." And my wife said, "Well what are the odds?" And he said, "Well, for you, it's 100% or 0." And she said, "Well, let's go." So, yeah.

Alicia: Yeah. Like you said, you don't have the time to mull it over for that long, yeah.

David: When I grow up, I want to be as tough as her.

Alejandro: That, that is one of the scariest things though is hearing how, how close, yeah, how close to death you really are.

Alicia: Yeah.

Alejandro: So my brother, when he got the first treatment of chemo, he had his appendix burst.

Alicia: Oh, my gosh.

Alejandro: He didn't know it. We were in San Antonio and, uh- and he was just complaining he's got a little bit of pain on the side. And I was making fun of him because we had, and there's a restaurant that's, uh, in Northern Mexico that's really popular for grilled chicken; and there happens to be one in San Antonio. So it's called the El Pollo Loco. I'm like, "Man, you don't want El Pollo Loco?" And he's like, "No, I've got a, I've got a pain right here. I'll only eat a little bit." So, shoot, I'll eat it. I'll eat it then, whatever.

And, uh, I don't know if it was that day or the next day, when, when he told the doctor, the doctor started like pushing on his abdomen, checking his labs. "Oh, we're going to send you to go get a scan." He thought it felt fine, but he wasn't sure.

So they sent, sent him down; and then, uh, they're like, "Yeah, you know what, your appendix burst. We need to get you into surgery right now."

Alicia: Oh, my gosh.

Alejandro: He already got sepsis; so his blood was already poisoned. He was getting a fever, but it was-, it wasn't going away. And the doctor said, "I think, uh, if you'd have waited another day, you probably could have died." We're like, "Oh, well good thing we did it now."

Alicia: Yeah.

Alejandro: So that's, that's the scary part of that.

Alicia: Yeah.

David: Yeah.

Lizette: A lot of patients and caregivers say that, um, when they're in the midst of it, you know, they're, they're battling the war. So they don't have time to think of what they're going through. But then once the patient gets into remission, um, usually the patient and caregiver both realize, "Oh, my gosh, look what we just went through." You may not realize it then, but after you, you start to say, "Oh, my gosh, you know, that was something serious."

Mirinda: Oh, we're not in remission yet, so I-

Lizette: Okay.

Mirinda: I'm not sure on that part yet.

Lizette: So you're still battling that.

Mirinda: We're still, yeah. We go Wednesday for a biopsy though, so Wednesday we'll know for sure where we're at. But, no, we're not there quite yet.

Lizette: Okay.

Mirinda: So can't quite answer that question yet.

Alejandro: I don't think we see it that way, what he went through, because we saw it then and now as like, "Whoa." Or you then, you make it, you know, we still, we still see it like that. I suppose it's pretty bad, you know. We usually make light of the situation-

Alicia: Um-hmm.

Alejandro: -as it, as it comes. But we are-

Alicia: And that's also a way of getting through it.

Alejandro: -how mad it is, yeah.

Alicia: Yeah.

Mirinda: Yeah, you've got to have some laughs in there.

David: I don't think that we have any of those moments per se, you know, as far as reflection. Uh, but in a way we do because we got involved with like, uh, ACS. We both were on the local board. Uh, we did the, uh, a lot of trying to get people on the registry.

Alicia: Um hmm.

David: Yeah, through an organization called Love Hope Strength. And, uh, so that kept us in, uh, uh, an extreme kind of cancer loop. And, unfortunately, what happened through that process is we did get to see people die because of, of their cancers.

Alicia: Um-hmm.

David: So those are the times that we kind of reflected and said, "You know, we really just looked back and noticed how lucky we really were.

David: And so those are tougher times when, when someone passes because you just, you look back and you. It's not a why me or a why us? You know, why were we so lucky? It's just, it's just so sad that so many people didn't make it.

Alicia: All righty, well guys, is there anything that you think we didn't cover that a caregiver listening would benefit from?

Alejandro: Don't give up because if you give up, that's pretty much, you know, game over. Like a positive attitude. Yeah, it helps.

Mirinda: Yeah, it does.

Alejandro: It feels like you're alone, yeah.

Alicia: Yeah.

Mirinda: And then we find you guys.

Alicia: Oh, yeah.

David: Yeah, thanks for all you do.

Alicia: Thank you.

Lizette: Thank you, yeah. Thank you for letting our caregivers know that they're not alone.

Alicia: And we really wish you and your loved ones well. David, Mirinda, and, one more time for the listeners?

Alejandro: Alejandro.

Alicia: Thank you so much for joining us today.

Mirinda: Thank you.