

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Patient-Doctor Perspectives: Shared Decision Making'

Description:

Join us as we speak with Donnie Hill, a chronic lymphocytic leukemia (CLL) / small cell lymphocytic lymphoma (SLL) patient and his doctor, James Essell, MD, of Oncology Hematology Care, Inc. in Cincinnati, OH. In this episode, Donnie and Dr. Essell discuss the importance of shared decision making (SDM) and how they worked together to determine the best treatment course for Donnie's CLL/SLL. Shared decision making is a key component of patient-centered healthcare that balances risks and expected outcomes with patient preferences and values. Be sure to tune into this real-world example of how SDM works and how patients can have open communication with their healthcare team.

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 with Donnie Hill and Dr. James Essell. Donnie was diagnosed with chronic lymphocytic leukemia, or CLL, and small lymphocytic lymphoma, or SLL, in 2008. Donnie has had multiple treatments throughout the years and remained cancer free from 2014 until 2021 when he relapsed again. As he has gone through these treatments, he has worked side by side with his doctor on which treatment would be best for him. He shared his CLL journey on a recent podcast episode, *Anxiety and Hope: Living with Chronic Lymphocytic Leukemia*.

Throughout Donnie's cancer journey, he has joined the fight with LLS to promote patient care and the development of new treatments. We are happy to have him back with us today to share his experiences on making treatment decisions with his doctor.



Dr. James Essell is a hematologist/oncologist, blood and marrow transplant expert, and cellular therapy specialist at Oncology Hematology Care in Cincinnati, Ohio. He specializes in malignant and benign hematology and blood and marrow transplantation and is actively involved in clinical trials and research. Dr. Essell is always in search of new and innovative treatments for his patients.

In this episode of our *Patient-Doctor Perspectives* series, we will be discussing shared decision-making, which is a process in which healthcare providers and patients work together to make decisions regarding treatment.

Welcome Donnie and Dr. Essell.

Donnie Hill: Thank you for having us.

James Essell, MD: Thanks.

Elissa: So let's start with Dr. Essell. What got you started in the field of medicine and then focusing on blood cancers?

Dr. Essell: So I actually started out in pharmacy college. I was a registered pharmacist.

Elissa: Oh!

Dr. Essell: Personal history. Our family carries one of the cancers genes and virtually everybody I knew growing up as a kid had cancer, so that got me into oncology. And then I like the hematologic malignancies. It's interesting that as a physician you can see the disease. In other words, you can do the bone marrow biopsy yourself; you're not sending them to the surgeon. You look at the slides in the microscope to see the disease. You have from the very beginning to the treatment to hopefully cure, at least controlling the disease, you're able to manage the entire spectrum and that's what I liked.

Lizette: Dr. Essell, our main focus today is on shared decision-making, but as we'll be discussing Donnie's diagnosis throughout the episode, could you define CLL/SLL for our listeners?

Dr. Essell: So CLL is chronic lymphocytic leukemia. It's a B-cell malignancy. Typically, nowadays it's found on a routine blood test where the white count might be slightly elevated, and CLL is where the cells are mostly in the blood and marrow. SLL, or small lymphocytic lymphoma is really the exact same cancer cell but, in those patients, presents more with enlarged lymph nodes and potentially the white count's not as high. Sometimes it's very clear. They get a white count of 200,000 and no enlarged lymph nodes or enlarged spleen, but usually it's more of a blend between the two that there's enlarged lymph nodes and an elevated white blood cell count; but they're essentially the same disease.

Elissa: Now Donnie, you were diagnosed with CLL/SLL in 2008. What signs and symptoms did you have that led to your diagnosis?

Donnie: Well, it's like I had shared in the previous podcast, I've always had not a very good immune system, so I got a lot of infections. My lymph nodes would swell and go away, or I had a sore throat.

Well, I got, I thought it was just actually a little pimple at my hairline in the back of my neck and didn't think much about it. I really thought well it's just, a fester; it'll go away. In fact, we were planning on going on a cruise and I had the audacity to make the joke, "Well if I don't make it to the cruise, guys, you're going to have to have a drink with an umbrella to celebrate my life." Little did I know what was coming toward me.

And so we went on the cruise. I came back. That one little nodule turned into two. So I went to see my family practitioner. He didn't think it was anything, but he said, "I'm going to send you to a surgeon. We can check it out, and we'll figure out what it

is." So, of course, like all good people, I went straight to Google to see what that could be.

Elissa: Of course.

Donnie: And I had a long list. I was ready to instruct the surgeon exactly what it was. And he came in and, literally, he felt it and he's like, "I'm sure it's some kind of cancer, but I don't know what kind. We'll have to do a biopsy and we'll order a CAT scan."

So I'm like, "No, no, no, no. It can be a lot of things besides that." But nonetheless, the CAT scan they were able to schedule quicker. I went in did the CAT scan, and I can still remember the Friday I got the call from the doctor's office it was pouring rain down, I was on my way to work, and they called and said, "We think you have tongue and throat cancer in addition to whatever is on the back of your neck."

They scheduled a biopsy for the nodules on the base of my tongue. And they all came back I have a knotty esophagus, but nothing was cancerous.

So then we went and did the biopsy on the nodule and it came back CLL.

Elissa: Wow! Now having been diagnosed 14 years ago, you've gone through multiple treatments. What are the treatments that you've done during that time?

Donnie: I've done two rounds of chemo and it pushed the CLL away. I came back probably about four years later and did just rituximab, four rounds and, again, it pushed it back. And then in 2014, Dr. Essell and I decided it was time to treat again and we decided on something called FCR, which was sort of the gold standard at that time of treatment for CLL/SLL. So I've had a couple rounds of chemo and the rituximab multiple times.

Elissa: And since the most recent relapse, have you been looking into treatments again?

Donnie: Of course, especially now. Beginning of this last year 2021, I got a CAT scan and it showed a little nodule on my arm, couldn't feel it, and over that year, it has grown exponentially, as well as some other nodules but the one is significant.

And the great news since the time of 2014 to today, as a patient, I have much better choices to be able to work with Dr. Essell on. Things like venetoclax is a newer drug, and ibrutinib was coming out right when I was finishing up with FCR; and both of those have shown great results.

And for me, my approach has always been if I use a treatment, I want to know I've got something I can go to if it's stops-

Elissa: Right.

Donnie: -working. And so right now I have two really good treatments. And there's some other things like CAR T but I'm very blessed that through the help of LLS, the medical field has really made advances in what we can use to treat my disease.

Elissa: Yeah. So now that you're looking into different treatments and trying to figure out which is best for you, that's a great segue into our topic today, which is shared decision-making. So, for our listeners who may be new to this term, I would like to provide a full definition. According to the National Learning Consortium, shared decision-making is a key component of patient-centered healthcare. It is a process in which clinicians and patients work together to make decisions and select tests, treatments, and care plans based on clinical evidence that balances risks and expected outcomes with patient preferences and values.

Now Donnie, Dr. Essell, do you both think that you used shared decision-making when you have communicated?

Dr. Essell: I think it's critical, especially in CLL where you have so many different choices out there, that you really need to go through with the patient, and I'll go

through that later, the details that you go into. But it's not just the doctor saying, "This is the next treatment." There's a lot more involved than that.

Donnie: Yes. And I think it's been critical for me. My mental health and that's one of the battles with CLL/SLL. You do these long periods of wait and watch. And it's sort of like, there's a contract killer out for you and they're not coming after you right now, but, sooner or later, they're going to show up. And so it's a little bit of that nagging at you all the time. You can reassure yourself; you know there's treatments, but you know it's there.

I remember the first time going to Dr. Essell and explaining, "Look, Dr. Essell, I trust you all. You'll be my doctor, but I'm always looking at test results and tracking research and I'm involved LLS and, I don't want that to insult you, but I'll be asking you these questions." And I remember so clearly, he said to me, "I would expect no less. You are fighting for your life, so, of course, I would expect you to come in with questions and bring things." So, I knew I had the right person just from that answer.

One of the critical parts that I think, from the patient side that needs to be pointed out is my number one tool to fight my disease is Dr. Essell. Dr. Essell spent a lifetime understanding this disease and working in research and he's the most valuable tool I have because he will share data. We can talk about results and what is best in my life, at 63-years-old and being a grandfather and being these things. And Dr. Essell takes those things in account.

So when I come in with questions, it's out of great respect to him. I don't come in telling him how to treat me. I come in with questions saying, "Dr. Essell, have you seen this research?" Or I remember just our last visit we were talking about the potential of putting these two drugs together and I was expressing concern about using them both up. And he was explaining to me how that wouldn't happen because he wouldn't use one very long. And so, it's those shared decisions.

And when I did FCR, I don't know if Dr. Essell remembers, but that conversation started out, "Should I do FCR or do another drug called bendamustine and rituximab?" And we discussed where I was at my age, what one could give longer treatment. So, it was all of those discussions. But at the bottom line, it's most important as a patient - first find a doctor that you do believe in. I'm blessed to have Dr. Essell. He's world-renowned. And I use him as my tool to go in and discuss and he always gives me the time I need. So, I go in with respect, "I have seen these things, I have read these things; will you help me navigate this?" And a good doctor like Dr. Essell always will help you navigate. And as Dr. Essell said, "There's no blue book you go to and say, 'Well at this point, you treat this way.' There's decisions that have to be made."

Dr. Essell: CLL is different too because people are taught get your mammogram, catch it early; get your colonoscopy, catch it when it's still a polyp. They present with CLL and you say, "Okay, you've got cancer, we're going to sit and watch it." And it goes against the grain of what everybody thinks. I literally was just talking to a patient a few minutes ago who is a new diagnosis CLL and she had seen a different doctor. This lady's 73, but she works out ten times a week, she looks like she's 50. And I said, "Could I make you feel better with treatment?" And she said, "No, I feel fine." "Okay, then why would we treat you?" And it's to get that shared decision-making of the first decision is when to start treatment. And then when you decide on that, then you start talking about which treatment to use. But there's also, as in Donnie's case, years where there's no treatment and things slowly progress. Sometimes they don't change at all for many years and when do you pull the trigger and then the discussion is what trigger do you pull?

Elissa: Now how do you go through this process with the patients? Are you sharing with them all the different treatments that are available? Are you going through and asking them what they would like? What is the process for good communication?

Dr. Essell: Well, the first part is, it's a shock. People find out they have cancer. My sister found out she had CLL by reading on MyChart. Called me at 10:30 at night,

"What does this mean? CBC is consistent with chronic lymphocytic leukemia?" "I'm too tired. It's 10:30 at night. We'll talk about it tomorrow." But you're shocked when you think all of a sudden you see the cancer word there.

And so typically we'll go in, we'll talk about everything. See them back in a couple months to reassure that things aren't changing. And then eventually they get tired of seeing me and we spread out to every six months, sometimes once a year, whatever we're comfortable with. That's part of the decision-making is how often to be seen and talk about reasons to treat. And that's you start losing weight, the white count's doubling. You're getting massive lymphadenopathy. The idea is treat before you get sick but don't treat too early. So kind of get into that anticipation phase, "Look, this is starting to really pick up. We might as well go ahead and get started. Don't wait until you're really ill." And it's all kind of decision. The person might have a vacation to go on and they want to do that before they get started. They may be changing jobs and insurance. There's lots of factors that go into play here.

Elissa: And now as we're looking at Donnie's situation that he just talked about, so then how are you deciding which treatment to go with? It sounds like he has a lot of options available to him currently after his most recent relapse.

Dr. Essell: Donnie is kind of like a new patient. It's been so long since we treated him. And, fortunately, his first couple of treatments we wouldn't even use anymore. FCR, his third treatment, we would still use in the younger patient that doesn't have high risk, but has a mutated, it's called immunoglobulin heavy chain. So there's one small group of patients that can get decades of remission out of it. Short of that, most people now are using more targeted therapy.

And there's really kind of two choices for someone upfront. And, again, I just had this discussion with someone a few minutes ago using what's called a Bruton tyrosine kinase inhibitor, or BTK inhibitor. It's a targeted therapy. Works on the B-cell specifically. There was the initial drug ibrutinib and then there's two second

generation acalabrutinib and zanubrutinib, and they all have potential different side effects. In general, the newer ones have less side effects. That's a pill that you take every day. That the vast majority of people go into remission and get many, many years of remission out of it, but it's also like taking your blood pressure pill, your diabetes pill; you're on this forever as long as it's working."

But it's easy. It doesn't require a tremendous amount of follow up. The other general class would be using this drug called venetoclax. It's a BCL2 inhibitor.

So, we start off with one drug and then slowly ramp up with the other drug. So there's more monitoring involved, there is an IV involved, a little bit more. But this is one that unlike the ibrutinib that puts people into a nice remission, can last for many years, well tolerated, this can put people into a complete remission. We call it MRD negative, minimal residual disease, that we actually do a bone marrow biopsy and use our most sophisticated tests and a significant portion of people will be in a complete remission. Those people can go many, many years without any therapy whatsoever before they relapse.

And some patients would say, "Give me the one that takes a little bit more intensive monitoring, a few more visits but I'd love to be finished with this in a year and not have any treatment for several years." And others say, "No, no, no, I don't want that. Give me something that's easier. I can come in once a month and eventually every three months. And even though I take it long term, I would rather do that."

And then you factor into this and, one thing I think is critical in this disease we've gotten these great new treatments but they're incredibly expensive. So we have a financial navigator right in the office. And as we talk about newer trials or combining these two together, you can be over \$30,000 a month in treatment costs just for the drugs.

Elissa: Oh my goodness!

Dr. Essell: So that has to factor into this. So maybe someone's saying, "Hey, I'm 63-years-old. Give me the venetoclax because I want to not be starting this when I'm on Medicare and can't get some of the deals and everything and deal with the high copays." So there's so many factors and you have to work with the patient, the patient's family to decide what's best for them. Ultimately, we don't know what one is better than the others as far as survival and you can switch. You can go from venetoclax back to a BTK or vice versa. But this is the ultimate shared decision-making of going through not just medically but side effect, number of visits, and economics, what works best for the patient.

Donnie: One of the things that was important to me in this decision-making, and Dr. Essell hit on it earlier, is how valuable wait and watch is. As he said, if you're feeling good, the thing I appreciate about Dr. Essell, he gets there's no drug that doesn't make you feel not good. All these drugs have side effects. Everybody has different ones, but you're going to feel things.

Over ten years the landscape has changed tremendously and in ten more years the landscape will change tremendously again, I'm sure. So every year I can go not treated, it gives me another year toward even better treatments with less side effects and maybe a cure someday. So wait and watch is so valuable to you as a patient. It's hard to do, but it is really valuable.

Dr. Essell: You're exactly right. Early in my career the only way we did better with cancer is to give more. And it was ways to trying to get more poison into somebody to get a better result. We're finally at the point over the last decade of better results with less side effects, and that's the goal.

Elissa: And that shows also kind of even more of a benefit, right, in opening communication and shared decision-making that you can really take a look together at other treatments that may help with a better quality of life.

Dr. Essell: Um-hmm.

Donnie: And what that definition of quality of life means. I think that's important for the patient to share his life or her life with your doctor. I mean Dr. Essell knows me very well. We talk about my grandkids and my job and trying to sell the business and these things. So it helps him, I think, help me navigate, "Look, I know you. I know what you're trying to do, what you're trying to accomplish, so I think this drug might work better for you." As Dr. Essell said, some of them are short term, harder to take, but, boy, can have big results; others are long term, those kind of things. So your doctor knowing you is real important.

Lizette: Yeah, and I think I want to highlight too what Dr. Essell said that in the beginning of the process you and the patient make sure that you speak about what you're both comfortable with in appointments. Whether the patient is comfortable seeing you every week, every month, every year, you have that discussion. And that's an open discussion. And we know Donnie here. We know that he is going to provide you with information and is open to speak with you.

I was wondering if you had patients that may not be as open as Donnie to tell you about the other factors in their life that they might be dealing with. How do you handle that when you're trying to provide that type of communication and service where you're trying to make sure that you find the best treatments for your patient, Dr. Essell?

Dr. Essell: Well, it is important to get to know them and I always try and pride myself and I treat people not diseases. And the other thing with CLL we're, unfortunately, living in this pandemic world. We're finally in a little bit of a lull. Hopefully it'll stay that way, but we all think the next variant is around the corner and will come back.

One of the things, and Donnie alluded to this earlier, is people with CLL don't make antibodies properly, have a lot of infections. And so that's one of the discussions that we talk about is, starting treatment could put you at a higher risk for COVID and also,

tell people if you have COVID, call me. Even if you go to another hospital. If they go and they stop their acalabrutinib, it may actually flare the inflammatory response and make COVID worse.

There actually have been studies looking at using some of these drugs to treat COVID. We're giving a lot of monoclonal antibodies for our patients that develop COVID that have CLL, and there's now a drug out that actually is a six-month sustained release monoclonal antibody, trying a little bit of a bulletproof vest for people that want to work and can't just live in the bunker the whole time. So, there's so many different factors involved, not just looking at the cancer, but looking at the whole person.

Lizette: Yeah, and you mentioned it before that you even work with your Patient Navigator, which can help with finances.

But that's also part of looking at the whole picture. It's not just discussing treatments, per se, but it's discussing everything.

Dr. Essell: As a physician, you can't just write a prescription for a \$17,000 drug and not warn the patient of what's going to happen. That's part of the discussion is it's going to take a while. It's expensive. It's going to go to specialty pharmacy. If you get this incredible copay, let us know, we'll work with you. And through The Leukemia & Lymphoma Society grants and many, many other grants that I don't even know about that our Financial Navigator saves patients hundreds of thousands of dollars a year.

I had one gentleman who was retired and, unfortunately, had saved his money and worked hard and so didn't qualify for almost any of the programs; and he's just, "I am not willing to spend that kind of money." And we were still giving him BR a couple years ago, knowing it was not the best treatment. But he just wasn't willing to spend that much. And eventually, we finally found a grant for him that fit into his economic status because you have to be pretty rich for \$20,000 a month in prescriptions, not to

hit the bottom line. That's not, something that anybody really saves for. It's a new car once a month and throwing it away.

Lizette: And Dr. Essell, why do you feel that it's important for doctors to work with patients to make those decisions together, not just you as the doctor making the decisions or the patient trying to make the decisions?

Dr. Essell: Well, I think a lot of what I do is education in my staff. And the more educated the patients are – everybody's not like Donnie, that's into the literature and looking it up, the better they can do. And they know what to call us for side effects. For example, we educate if they're on ibrutinib; and they're going to have surgery, even a minor knee surgery, call us. We can stop the medicine a week ahead of time, so they don't bleed. All that's part of shared decision-making. And from my standpoint, it's a lot of education, so we work together to get the best outcome.

Donnie: One thing I'd like to say too for patients, all doctors aren't equal. And if you go to a doctor and you're not getting good feedback or you feel like you're not having good communication, maybe the doctor's fine, and you just don't relate with that doctor. You need to walk away and find a practice and a doctor that you can relate with.

And do some research on that doctor. Dr. Essell is in all of these drugs doing research, he's chairing things. He stays on the cutting edge, so he can bring those technologies to the forefront that can share with me.

Not all practices are the same. As Dr. Essell says, OHC really puts a lot of infrastructure in place for people so they can navigate these extreme expenses.

I remember even, at one point, Dr. Essell said, "I'm going to give you a gamma globulin treatment for a few months". And so we did, I think we were doing six treatments. But somehow something happened with insurance, and all of a sudden insurance wasn't paying. I was like looking at \$12,000 a treatment; and it was once a

month and I had done four or five of them. And Dr. Essell and his staff stepped in and helped me navigate with the hospital, and we got it taken care of.

So as a patient, make sure the group that you're going to and the physician you're with is highly trained and highly skilled in your disease and is someone you can communicate with and will help you navigate all of the things you're going to face.

Elissa: Yeah, that's really good advice, Donnie. I particularly like wanting to find a specialist like Dr. Essell is really important. Sometimes, you do need to go and look for a second opinion so that you can find that good specialist.

That goes into kind of my next question. Donnie, in the last podcast, you talked about kind of being nervous coming in. You talked a little bit about it before, how you went in and you said, "Hey, this is my treatment, this is my life." But at the same time that can be a little nerve-wracking, right, because you want to show your doctor that you trust them and that you trust what they have to say.

Dr. Essell, what would you say to patients who may feel nervous about speaking up and communicating openly with their doctor?

Dr. Essell: A couple things I was going to say is if your doctor can explain it to you on your level, and that can be, they have to tailor it to the person's educational level. And as, myself as a physician, when I go in and see my eye doctor, for example, yeah, I did ophthalmology in 1985. I hope they've advanced since then. I want them to explain it to me like they would anybody else. So, we try and bring it down, and that's not being judgmental or anything, but so that people understand. And if you realize they're at a higher level, you can bring it up.

The second thing is, when people do want a second opinion, they usually do one of two things. They don't tell you, and that's not good because then they don't go with all the right information, or they sheepishly ask, "Is it okay if I get a second opinion?" My response is, "100% of the time if your doctor doesn't want you to get a second

opinion, you need a new doctor" because you're not hiding anything; and you hope that they're going to see somebody that's going to say, "Yeah, what they said makes sense." And, like Donnie says, if they just happen to communicate better, that's what they should do. Everybody doesn't always mesh together.

Elissa: Now, Donnie, you've been a big advocate for yourself when it comes to deciding on which treatment course to take. Why do you feel like it's important for patients to advocate for themselves and their treatment?

Donnie: Well one thing I would circle back to, CLL/SLL is primarily an older person's disease. It tends to be over 60. Now I got it earlier than that, and people do. But I say that, and I think my generation of people, 60s, 70s, we were taught to respect authority.

So people my age, a lot of times, is hesitant. We don't want to show any disrespect to the physician going in. We recognize this is a very prestigious person I'm speaking with. And so sometimes we're hesitant to broach the subject just because we don't want them to have disrespect.

And I would say to a patient, again, it goes back to how you address your doctor. Don't go in saying, "I've figured this out, and this is the treatment I'm going to do; and I read this, and I saw the commercial." You know, go in with studies or go in with good questions, and ask your doctor how do I navigate these things? How do I understand this literature? I don't understand these questions.

Another thing I think is very important, especially early, is take someone with you. As Dr. Essell said, when you first hear you have cancer, I don't care how tough, how strong, how you are, your legs get knocked out from under you. That's a scary word to be associated with your name. And so it's hard to hear everything, and you're going to start hearing medical terms that you've never heard in your life. So having a person with you can catch things that you might miss and write things down. The doctor's not



going to take that as an insult if you write it down or say, "Will you spell that for me?" or "How do you say that word?"

Medical terms can be very unnatural to the average person. So to me, the things that's important is do some research. Call LLS. There's a 1-800 number you can call at The Leukemia & Lymphoma Society (Information Resource Center), and you will speak with a master's level nurse or social worker that's highly trained in your disease and what you're going to be facing. They can even provide good questions to ask.

Make sure you've got some idea of how you want to approach it. Maybe you want to look at treatments. It's not hard to find these treatments. They're out there. But do a little research. Kind of understand what your disease is, and then that can begin the question and the back and forth. You're going to live. You've got to figure out how you're going to live with this disease, and there's options. So start planning to live, not plan to die.

And today that's truer than it's ever been with CLL and SLL. It's not fun to navigate. I wish I didn't have it. But as you go in to ask these questions, talk to your doctor about how can I get the best quality of life for me and what I want, and how can we deal with this? And have someone with you that can write things down and make good notes.

Elissa: Yeah, that's really important.

Now, Dr. Essell, we've talked quite a lot about CLL or other chronic leukemias. But is a process like shared decision-making good for all blood cancers?

Dr. Essell: Absolutely. The first thing I would reiterate what Donnie said, don't go into your first appointment alone. Because you'll just be blown away; and you won't hear half what's going on. You can go home that night and sit down and exchange notes.

But it is for any cancer, especially, well, upfront, what is the best choice because oftentimes we do have choices now. But especially then when you get into relapsed disease, what are your goals? How aggressive you want to be?

I'll give you an example. We had a young man; he was diagnosed with CLL with a white count of 400,000 right after he graduated from UC at 22. And this was a long time ago, before we really had a lot of these treatments. We gave him six cycles of FCR, which put him into a nice remission, not a complete remission, and talked to him about an allogeneic stem cell transplant, which is something we very rarely do because there's so many other good treatments.

But this guy was 22, and then actually we discussed it with CLL experts throughout the state of Ohio; and a lot of them are, "Oh, I wouldn't do that. He could live another five years," what they said at the time. His goal wasn't to make it to 27, and this young man is now about 40 years old, in complete remission, cured of his CLL, one of those rare people.

And he had a lot of complications for years to get to where he is now. But ultimately, he didn't want to live off and on chemotherapy and die before he was 30 years old. So it is definitely shared decision-making. What are your goals? And sometimes, let's say, it is your goal, to make it to Christmas. We can use this easy treatment. If your goal is to make it, to Christmas ten years from now, we've got to be more aggressive.

Lizette: I think that's the most important thing, really, is to know somebody's goal because I think sometimes, we all assume we know what somebody else wants. But that's not true unless we ask the person, we don't know.

And I do want to highlight certain things that you said, Donnie. Do you find, Dr. Essell, that different generations communicate with you differently?

Dr. Essell: Well certainly the technology is different. The people that are much older may not be as savvy on the Internet; and they'd much rather have a book that we can

give them that explains what's going on whereas the younger person already has it printed out or it's on their iPhone before they come in.

There's just a difference. I think of what Donnie was saying, older people are maybe a little bit afraid to question the physician whereas younger people wouldn't at all. And that's okay.

Lizette: Yeah, definitely. And I know that we just brought up caregivers. Are caregivers able to be part of that shared decision-making? Do you have to have permission to include the caregiver?

Dr. Essell: Well, that's why I always want someone at, at least the first couple appointments when the decisions are made so they can go home together and decide what works in their situation, especially if the caregiver is a child for an elderly parent. They'll come in and say, "Oh, we'll do everything for mom," and then they realize, they're on their 25th appointment over the year, and it's getting old. And maybe they don't want to keep doing that or that mom doesn't want to do it. So they need to be involved upfront, and they'll understand what they're willing to do and maybe the parent doesn't want to have their child spend so much time taking care of them. It's delicate and difficult decisions, but it requires multiple players.

Donnie: When you're trying to think about someone that's going to go in with you, the person I want by my side is someone that can listen and hear and has the ability to interpret some of these things or help you figure it out. And sometimes you want someone that can give you, well how did you take that? How did you see that? If there's too much emotion, sometimes they can't share effectively with you. So it's a big decision who you bring along. And whoever you choose, they'll probably need to be a little bit long term, that you can count on going to visits every few months for a while.

Lizette: Sure. And Donnie, I know that you as a patient have been able to really connect and communicate with your doctor. How do people tell their doctors their preferences? Does it have to come from you, the patient, or do doctors ask you?

Donnie: I think it's, again, a combination of things. It's not just, well, I would prefer to take drug X than drug Z. It's, unfortunately, not that simple. It's more of talking about what each of these drugs do, what are the side effects, what are the possible results-

One of the reasons I chose FCR instead of bendamustine was because I was young enough, and I'm pretty healthy, and I thought I could handle that more aggressive chemo as compared to bendamustine and get a longer remission. And I think I made the right decision. It's worked for me for seven years. And now, I knew it would come back at some point, and it's back.

And so we when you're having that discussion. It's more of, you know, I'm planning on living to my 80s. So how am I going to get there? And I'm not okay with just being a couch potato. I'm active with my family and my children. So, which one of these drugs is going to help me maintain that?

And through those conversations, obviously, the doctor's learning about you. You're learning about the medicines that are available, and good decision-making comes out of it.

Lizette: Dr. Essell, if somebody is not as open as Donnie, do you ask patients if they want to hear more or less about the treatments or how they want you to tell them about the possible treatments?

Dr. Essell: I'd probably give them more, unless they shut me down, because I just feel it's really important that we're all on the same page, people understand the goals, the potential side effects. They're pretty well informed, and after I finish talking to



them, the nurse practitioners and the nurses all have educational sessions with them, so everybody knows what we're getting into.

Lizette: Yeah, and Donnie and Dr. Essell, to finish off our episode on Shared Decision-Making, what would you say as a final encouragement to both patients and doctors on the benefits of working together to make decisions about treatment as well as other things? Not just treatment.

Donnie: Well for me as a patient, having Dr. Essell, and I was blessed with the physician I had before Dr. Essell. I've had two great physicians that's made this road much more navigable. No one wants to hear you have cancer. No one wants to have to make these very hard decisions about treatments. But having a good team and your number one tool is your physician, having a great physician that you have confidence in, you respect, that you feel like, as Dr. Essell says, he's not just treating a cancer patient. He's treating Donnie Hill. He cares about me, and he knows me.

And having that has made all the difference in the world. That and having good support systems like The Leukemia & Lymphoma Society. The more you can surround yourself with support systems that help you get good information, helps you stay in the middle of the road, having faith.

So having good support systems around you of things you can believe in, first and foremost, a good medical team in your position, I believe, is so critical; and it makes a big difference in your mental well-being because I have confidence. I know Dr. Essell's given me the best advice possible.

Dr. Essell: So from my standpoint, I think education's good, and a lot of patients realize that you're in it together. Our office is unique that we're actually open 365 days a year.

Elissa: Wow

Dr. Essell: Yeah. It's the right thing to do. So if someone calls on Saturday morning and, they're ill, we see them on Saturday morning or even on Christmas day. And that's not something that just happened, that people like to do. We do it because we're taking care of blood cancer patients that are potentially critically ill but also have the potential to do well long term, and we want to do everything we can to make sure the outcomes are the way they should be.

So it's a team approach with education, knowing what to call for, and what their goals are. And the goals should be to have the longest life possible with the best quality of life.

Elissa: That's great.

Well thank you so very much, Donnie, and Dr. Essell for talking with us today. I think this is a really good discussion on shared decision-making and how it benefits patients.

But not only that, we talked about the process of it and really how it works in a real-life situation. So thank you for being here. For our listeners, we actually have an interactive shared decision-making program that you can kind of put yourself through one of these situations with your doctor and learn how to communicate. So stay tuned till the end for that. Thank you again, Donnie and Dr. Essell, for being here with us today.

Dr. Essell: Thanks, Elissa. Take Care.

Donnie: Thank you for the opportunity to give back. I appreciate it.

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. 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.

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](https://lls.org/PatientSupport). You can learn more about shared decision-making through an interactive program that can be found at [LLS.org/Programs](https://lls.org/Programs) under Leukemia and then Chronic Leukemias.

There is also more information on chronic leukemias at [LLS.org/Leukemia](https://lls.org/Leukemia). 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.