

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Healing Through Writing: An Odyssey Through Acute Myeloid Leukemia (AML)

Description:

As a cancer patient or caregiver, telling your story can not only be a way to update loved ones about your condition or be a comfort to current patients, it can be healing for yourself. In this episode, we speak to Steve Buechler about his treatment for acute myeloid leukemia as well as his experience through survivorship.

Steve shares how writing helped him heal from the emotional effects of cancer. As an LLS volunteer, he now facilitates writing workshops for our *LLS Community* and wrote an article about how language matters when speaking to patients.

Join us to hear about Steve's "odyssey" through AML, which he describes as not something he chose, but something that taught him more about life and himself.

Transcript:

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

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

Elissa: Today, we will be speaking to Steve Buechler, an acute myeloid leukemia, or AML, survivor diagnosed in June of 2016. After chemotherapy and a double cord blood stem cell transplant in October of 2016, he reached complete remission. Since then, Steve has been very active in the cancer community and with LLS. He volunteers for the Patti Robinson Kauffmann First Connection® Program and is offering a new writing workshop for patients and survivors as he strives to help others in their healing and recovery from the emotional effects of cancer. Steve also wrote a memoir titled, "How Steve Became Ralph," which chronicles his odyssey through cancer and stem cell transplant. Welcome Steve.

Steve Buechler: Thank you very much. Glad to be here.

Elissa: So let's start with your diagnosis of acute myeloid leukemia, or AML. Did you have any signs and symptoms and how did you end up getting diagnosed?

Steve: I did not have any signs or symptoms. In fact, back in the spring of 2016, I was feeling perfectly healthy. I was wrapping up a semester of college teaching, looking forward to one more year of teaching; and things were so good that I almost skipped my annual physical exam. But at the last minute I thought, well, I'll go in.

And so I did that, and my doctor did some bloodwork and discovered that my white blood cell count was dangerously low. I had no idea what that meant, but he thought he should refer me to a hematologist. The hematologist said, "I think we should do a bone marrow biopsy." I had no idea what that entailed, but I thought, well, you should know best. So, I complied with their recommendations and their referrals, but it never occurred to me that I could have cancer. I had no symptoms. I felt perfectly fine. I'd been in good health my entire life. And somewhat naively I assumed that, if a person has cancer, they somehow know it. I learned differently down the road.

So, I went in for the biopsy. I returned home in the afternoon and my wife said, "Hey, that doctor called and wants you to call him back." This is about 48 hours after the biopsy. I placed the call and I sort of confidently thought, this is when they're going to tell me the biopsy was fine, and they can rule out all the bad stuff.

Not even close. In a ten-minute phone call, he said I had AML with about 50% blasts circulating in my bloodstream, I needed to get to a hospital immediately, and they booked an appointment for me first thing the next morning.

Jesse: Wow!

Steve: So, I have very little recollection of the rest of that day. I was just in shock. I was in a daze.

The next morning, we drove to a hospital that was all the way across town and met with a doctor who did a very nice consultation and ended up saying, "Given what

you're going to go through, I think you'd be better off if you could be at a hospital closer to where you live on the other side of the Twin Cities. Some phone calls were made, some arrangements were made. I ended up in a hospital much closer to my home, and I later learned how convenient that was going to turn out to be.

Got into a room only like 72 hours after the biopsy and 24 hours after the results. There was a rough period the first, you know about 10 to 12 days into the chemo regimen, which was the classic 7+3 cytarabine and idarubicin. They said, "You're going to feel really bad for about a week and a half." Now I got to the 10th day. I didn't feel very bad, and I thought, hey, maybe I got this thing beat. It turned out it was a little premature because the next day, all the predictable side effects hit. Colitis and *E. coli* infection, a full-body rash, fevers.

By about the 4th week, counts were recovering, symptoms were receding, I can sort of see light at the end of the tunnel, and I finally got my discharge papers on my 37th day of this hospitalization that began with basically no warning. It was quite an introduction to having acute myeloid leukemia.

Elissa: Yeah, sounds like it. Now we know that the prognosis and treatment of AML can be determined by your gene mutation or chromosomal abnormality. I'm an AML survivor, and I had inversion 16. What type of AML did you have?

Steve: Well I think back then, the tests were a little slower to come back than they are now, so it took a while, but what they established they checked for the FLT3 and I was negative for that, which is a good thing, and they checked for NPM1 and that was also negative, although it turns out that might've been a beneficial mutation to have, and I had a normal karyotype.

And what they told me going in is that once we have these results, we can put you in either a high-risk or a low-risk profile and that will help inform further treatment. And when these results came back, they said, "Well, actually, you're in kind of an intermediate group." I had been anticipating a really clear fork in the road and an

automatic decision, and that was sort of tossed back on my shoulders about what kind of further treatment should I pursue.

That sent me back to my community oncologist and we talked about the possible risks and rewards. It came down to multiple rounds of consolidation chemotherapy to try and maintain the remission or a stem cell transplant. And everybody I talked to was kind of noncommittal and they'd give me risks and rewards, but they wouldn't really give me advice.

At that point, my wife, who's smarter about these things than me, said to my oncologist, "If Steve was your husband, what would you want him to do?" And she immediately said, "Get a transplant." So, my wife elicited that kind of advice with that kind of question.

I also got second opinions from the Mayo Clinic. They also said, "You'd probably be a pretty good candidate for transplant. We don't see any reason you shouldn't do that." So that added to my original visit with my transplant oncologist where she told me, at that point in time given the condition I was in, "If you did consolidation chemotherapy, your five-year survival rate is about 33%."

Elissa: Oh yeah.

Steve: "But many people can't tolerate the toxicity of the treatment and they have to stop it before they get all the benefits." That didn't sound real good. She said with the stem cell transplant, there was closer to a 50% chance of survival five years, but you had to first get over a 15 to 20% risk from the transplant itself. So, the overall odds weren't really much better. That's what I was juggling with all this advice.

And finally the logic I hit upon was that, if I had further chemotherapy and it didn't work out, I would always really regret not getting the transplant.

Elissa: Right.

Steve: If I had the transplant and it didn't work out, at least I would feel like I gave it my best shot. With that logic, I thought I'm going to commit to the transplant. I've done as much research and studying as I can, so let's open that door and see where it takes us.

Jesse: For transplants, we often hear about stem cells coming from bone marrow or peripheral blood. We don't hear as much about stem cells coming from umbilical cords. Could you tell us more about that and what the difference is between those different ways of obtaining stem cells from the donor?

Steve: Sure. The first thing that they did, I think as they typically do, is they considered related family donor sources like brothers, parents, children sometimes. I had one sibling, and they tested him, and he was a haploidentical, a half match with me. That's a workable, but not necessarily an ideal donor source. So, we were pondering that and then they said, "We could also consider umbilical cord blood donor sources." That sounded like science fiction to me. I had no understanding what that was about, but they explained it-

Jesse: Yeah.

Steve: -that for some number of years, women all over the world have donated newborn babies' umbilical cords that are genetically typed, frozen, and stored, and catalogued for use in a future transplant. And the interesting part about this donor source is usually umbilical cords are just tossed away as medical waste, but if you go through this process of preserving them, they can be an equally effective donor source for people needing a transplant, like myself.

So, again, I found myself asking my doctors, "Well, which is better? Should I go with my brother as a half match or go with whatever cord blood sources you can find?" And they said, "Well, we don't know the answer to that question. What we know is that with half-match donors like your brother, there's a higher risk that you'll have

graft-versus-host disease (GVHD)" because half of his cells don't match my body, but it tends to engraft a little quicker so that's an advantage.

With cord blood, the cells you're getting from that umbilical cord are naïve. They never lived in another body and so they're less likely to lead to graft-versus-host disease, but they can take a little longer to engraft, which leaves the patient in danger because they're immunosuppressed after transplant. But the five-year outcome was roughly the same.

So, again, I threw my hands up in the air and said, "Well what do I do?" And they said, "Well, we just happen to have a clinical trial comparing these two donor sources, and you would be a good candidate." I could either have chosen my brother or cord blood or tossed my hat in the ring and let them randomly assign me to one or the other.

So that's what I did, the morning after I entered the trial, they called me back and said, "You've been randomly assigned to the cord blood option. We will now investigate that more thoroughly and more exhaustively and find the best cord blood donor sources that we can find for your transplant."

Elissa: That's very interesting. You don't think about that very much, having umbilical cords donated and that they've been doing it for quite a while now and putting together, essentially, this registry. So that's great.

You've now been in complete remission for over six years, which is so exciting. As many of our listeners know, cancer comes with emotional effects that can last long after treatment is over. What have you done to cope with those emotional effects?

Steve: It really started from my very first week in that first hospital. Looking back, I think I intuitively or organically responded to what was going on in ways that I've later come to think of in a more systematic or codified way. I developed coping strategies that helped me from the beginning right to this day. And what I've learned is that



these strategies don't just apply to surviving cancer treatment. They apply much more broadly to life in general.

The first one involved the trifecta of mindfulness, meditation, and yoga. There's another deep irony here because I dabbled in that stuff on and off for years, but it was just two months before my diagnosis that I saw an invitation to a community education class on that topic. And I thought maybe it's time for me to get a little more serious about this. So I took the class; it was very good. And it convinced me that I wanted to integrate this into my daily life. I started doing daily meditation, yoga, which I see as two pathways to the ultimate goal of just mindfulness, a nonjudgmental awareness of the present moment and an ability to just not ruminate about the past or being anxious about the future and just stay in the moment that you're in.

And I had about eight weeks to internalize that whole approach. And one of the gurus of this process, Jon Kabat-Zinn, claims that if you practice this systematically for as little as eight weeks, you can rewire the way your brain works and the way it processes your experience. So that was what I had in my arsenal as I entered the hospital, and I'm absolutely convinced it helped me tremendously because for much of my life, I could've been mistaken for a chronically anxious control freak. It didn't take much to get me to, "Oh what's the worst-case scenario? How can I anticipate this? How can I plan for that?" And mindfulness just let me let go of all of that. It was an extraordinarily simple, but powerful way to stay calm. And so, I just incorporated that into my daily routines in the hospital.

My first hospital I asked about a yoga mat because I didn't have time to bring my own. Every night, I would do my yoga. Related to that, a second strategy was to engage in as much physical activity as I could. The last thing I wanted to be was a passive patient lying in a bed. That just didn't fit with who I was or who I wanted to be. I might be one of the rare people when the physical therapist came to my room, I actually welcomed them and I said, "Can you give me some stretchy bands? Can you

teach me some isometric exercises? Can you tell me how I can use my hospital room as a kind of a gym?" And they were eager to do that.

But the most important thing I hit upon is I started roaming the halls. I had permission after my chemo was done to leave my room and even to leave my floor, and I loved getting out of my room, seeing other people, and roaming around the hospital. The routine became walking in the late morning, walking in the late afternoon, walking before bedtime first just on my floor, then all over the hospital.

About a week into this, the nurses said, "We've been watching you and we think you're probably walking about five miles a day," which was hilarious because I never walked that much until I was in a hospital. What I didn't count on is as I made these trips around the hospital, I kept encountering nurses and staff and other people over and over and pretty soon we're waving or we're smiling or we're winking or we're telling stories if time permits. And I don't think they will ever appreciate how much it means to a cancer patient, at least to this cancer patient, to be seen and recognized and acknowledged as an upright person who can walk and do this as opposed to a sick patient in a bed. It just meant a whole lot to me to have these brief social connections with all these great people. So, it wasn't just physical activity, it was the social aspect of being up and about and outside the room that came to mean a lot.

The third strategy, just a very general one. I wanted to be as proactive as I possibly could. That meant everything from reorganizing my room, rearranging the furniture to suit my needs, making my bed every morning. They had housekeeping people who would do that, but to me it was symbolically important to get up and say, "The night is over, I'm going to make my bed." Really a little symbolic thing, but it was a marker, again, of just being able to do something active and exert a little bit of control over this very tiny world of my hospital room.

Jesse: Absolutely.

Steve: I was also very determined to be proactive in my relations with nurses and doctors. It started as a strategy to kind of cultivate good relations with my nurses so they would treat me better, but it turned out to be just inherently fulfilling to move into a more interactively personal relationship. Not just a medical encounter, but we know a little bit about each other as people as that just made it much more meaningful to me. And with doctors, I was pretty relentless with my questions, "Why does this work? Why are we doing this? Why aren't we doing that?" They were very patient and took the time to make me kind of a collaborator in the treatment that I was receiving.

Jesse: Now we mention in the introduction that you have done quite a lot of writing since your diagnosis with AML. How did you get started and why is writing important to you?

Steve: I started with no intention whatsoever of writing a book or even writing on an ongoing basis. I started because the second day I was in the hospital my wife had just arrived, our house is essentially abandoned. We had no warning whatsoever that this was going to happen, so newspapers were piling up, the mail was piling up, the lawn wasn't getting cut. So, I composed an email to a group of neighbors, and I said, "You may have noticed that we haven't been around for the last four or five days. Here's what's going on. Here's what we need. "

Jesse: Yeah.

Steve: I immediately realized this was an ideal way to keep people informed about what was going on. The address list for these emails grew to a dozen and 30 and 50 and, ultimately, over 100 people.

Elissa: Wow!

Steve: The next thing that occurred, probably within a month of these informational emails about updates, is I began to realize that writing for other people was really

therapy for me. I mean, it was a real nice opportunity to put together all these chaotic pieces that were out there and integrate them into a story. That's basically what I was doing. I was telling a story of what's going on, what I expect to happen next, how I'm reacting, how I'm processing the emotions. Sometimes the news was not particularly good, so I also ended each email with a joke. And I specialized in really, really bad jokes. You know, terrible, terrible puns.

And it turned out that a lot of people really resonated with the jokes to the point where if I forgot to include a joke, people would write back and say, "Well we hear how you're doing, yeah, yeah, but where's the joke?" So the presence or the absence of the joke became a running joke itself, and it allowed people who didn't know what to say to me as a cancer patient to still relate to me as a person who's always had this twisted sense of humor. It was just another pathway for people to connect.

Elissa: Yeah.

Steve: As that went on, the emails got more and more reflective, they got longer. I sort of pondered all kinds of existential issues. It was an ongoing process of just trying to make sense out of what the heck was happening to me by putting it into some kind of narrative sequence.

There's a sociological concept of what they call narrative identity, that who we are is a function of the stories we tell about ourselves. And before I even had that concept in my head, I was sort of doing that. I was reconstructing and maintaining my identity by writing these emails. And I'm convinced that if I had not been writing for an audience, I would not have arrived at some of the insights I did about my disease and my treatment.

Elissa: Wow!

Steve: I had to understand it more clearly myself in order to tell them about it. It's a little bit like teaching. If you really want to learn something, teach it, because you

have to understand it at a deeper level to teach it and to share it with other people. For me, writing became a way of healing in the face of everything that cancer can do to you.

Elissa: Yeah, absolutely.

Steve: I had two correspondents, one was a distant cousin wrote back one day and he says, "You know, this is a pretty interesting story, maybe you should write a book." And I rolled my eyes and said, "Come on." And then my brother said something similar independently of that comment. And I just thought, that's not what I want to do. That's not what I'm meant to do.

Elissa: Yeah. It's quite the project while you're recovering from cancer.

Steve: Yeah. But it kind of lodged in the back of my mind. And when I got to that period about six months after transplant when I felt this identity shift from a patient to a survivor, I started playing around.

Hypothetically, if I were going to write about this, what might it look like? What format would it take? I began reading other cancer memoirs to see what the market was like and what people were saying. I came across one by a breast cancer survivor, who's book in part was based on emails that she sent when she was under treatment. I thought well I guess this has been done before in a sense.

Jesse: Yeah.

Steve: So, I contacted her publisher, and much to my surprise, a one-hour phone call was enough to secure a contract from her publisher for my book. And so-

Elissa: Wow!

Steve: -I went back to all those emails, edited some of the information that no longer applied, but left the emails intact. I wrote a preface and an epilogue to introduce it and frame it. That came out in December of 2018, about two and a half years after

my diagnosis started. The title may strike you as a little obscure, but I should tell you when I learned about my two donors – this goes way back to the transplant – I wanted to know more about who my donors were but basically, they were unknown infants.

It's a complete mystery I'll never resolve about who my specific donors were. But as the transplant day drew near, again, my odd sense of humor and playfulness, I was getting a double cord blood transplant – all I knew was one was a boy and one was a girl. So I named them Ralph and Gwen.

Elissa: Okay, so that's how Steve became Ralph.

Steve: Right.

Elissa: That's where that came from. Okay.

Jesse: And that makes sense.

Steve: And after transplant, they estimate for about three weeks I had both donors' cells circulating in my body with their unique DNA and blood type as well as my own DNA and blood type. And what typically happens with a double cord blood transplant is after about that two, three-week period, one of the donors kind of wins out over the other one and the other one fades away. And they could tell in a biopsy three weeks after my transplant that Gwen was no longer to be found. But Ralph was 99% engrafted.

Elissa: Wow! That's really interesting that they could see that. That's amazing.

Steve: Yeah. So the title of the book became *How Steve Became Ralph*.

Elissa: Okay.

Steve: I felt bad about Gwen because it seemed like if we'd known Ralph would engraft, Gwen could've gone to another recipient. But of course, you never know

ahead of time how that's going to play out. And at a later point, my transplant oncologist actually said Gwen may have played a more important role than I thought because for that period where both donor cells were sort of knocking around in my body, they were engaged in a bit of a sparring match with each other to see who would survive. And it's possible that Gwen's cells toughened up Ralph to fight off what he perceived as an infection from another donor. So, even though Gwen went by the wayside, Ralph was a tougher immune source after that by virtue of that little struggle between the two of them.

So Gwen is gone, but she may have played quite a role in strengthening and beefing up Ralph and Ralph has since been and continues to be very, very good to me. He never caused me any trace of graft-versus-host disease (GVHD).

In 60, 70% of transplants, there's at least some trace of graft-versus-host disease. I've had none of it.

Elissa: Wow!

Jesse: That's great!

Elissa: That's just truly amazing. And I really love the idea of sharing your story and sharing your experiences, particularly what you were doing in the emails and in the book. I think it's good for people that have not had cancer to really help them to understand what it's like, both the positive and the negative. Cancer patients, I feel like, don't talk as much about the negative experiences and the trauma that we go through. So, I love that you've been sharing in this way to help yourself but also get your story out to others about your cancer experience.

Steve: Benefits all around is what I like to think.

Elissa: Yes, definitely.

Jesse: Absolutely, yes. Now, obviously, you've been involved with many things. So, you've been involved with LLS with both First Connection, LLS Community, and now with writing workshops. We are so grateful for this at LLS, so thank you. Could you tell us a little more about your involvement with those?

Steve: The first of those that I did was I got involved in the First Connection Program pretty early. The process is, if a patient contacts LLS and says, "I'd like to have this First Connection," they try and match people by age or diagnosis or gender or whatever specifics the patient wants to have. And then we just set up a phone call and take it from there.

It's really deeply fulfilling to have learned something the hard way and then have an opportunity to share it with people who are going through the process.

Elissa: Yeah.

Steve: I try to be for those folks the person I wish I had had when I was going through it. And I could've, but at the time, I wasn't aware of these kinds of programs, so I couldn't take advantage of them. One of the big challenges for First Connection and similar programs is to somehow get the word out. As soon as a patient is diagnosed, it would be nice if they could be made aware that this is an option.

Elissa: Yeah. That support from already somebody who's already been through it and is maybe still going through it is just so invaluable to patients to share the experience and connect that way. I think it's wonderful.

Steve: Yeah. Everything you said is absolutely true according to my experience. And what was even more impactful is, for a couple years there after I recovered and before COVID, I also visited patients in person at both my induction hospital and my transplant hospital. And there's an added element when you're face to face physically in the same space. As a hospital volunteer, I'd get the names of certain patients from nurses and go down the hall and knock on a door and come in and say, "I'm Steve."



I'm a volunteer." And they look very cautious. What's this about? And then I'd say, "But I'm also a transplant survivor." And their demeanor changes in an instant. Suddenly they sit up, they get real attentive, invite me in. And I've had just some very powerful exchanges with folks like that. And it's not always that I have great things to tell them. Sometimes I do, but I think mostly, to go back to the power of writing, I'm giving them an attempt to tell their story-

Elissa: Yes.

Steve: -to someone who can understand it in a way that not everyone can.

Jesse: Yeah.

Steve: And just as writing was therapeutic for me to put it down on paper, speaking for them from a hospital bed across the room to a transplant survivor, on the one hand, they're impressed and happy to see a survivor, but they're also putting together the pieces of their identity through telling me what's going on.

Elissa: And you can understand with few words.

Jesse: Yeah

Steve: And I can't tell you how many times doctors and nurses have supported this effort, both through the phone calls like at First Connection and even in person because they get it too. They said, "We can do all kinds of medical things, but we can't bring the empathy and understanding "that someone who's been through it can bring."

Elissa: Yeah.

Jesse: Of course.

Steve: So, that's been fulfilling. I've been doing it now for probably five years and hope to do it into the indefinite future.

Elissa: That's great.

Jesse: Very good.

Elissa: And then you also have been involved in the LLS Community and writing workshops. Would you like to tell us about those?

Steve: Yeah. The writing workshop begins on April 14. I'll be doing this with one other individual, so we'll split the group into two, and we'll have four meetings over four weeks.

Each week there'll be a different prompt that people can respond to and write about. They do their writing in private, but then if they want to share some of their writing, they can do that. Within the Community, that's going to get a conversation going back and forth and people can react to other people's entries. I've done this writing workshop before, but it never had quite that dimension of interactivity over the four weeks that the thing will be running. And it's kind of a blend between a program that LLS did many years ago called *Pen My Path*, which I actually participated in 2017. And in a format that I've been using is based on some pretty interesting research about what kind of writing helps cancer patients and survivors. And what the research suggests is that they compared several groups with different types of writing. They had some people do what they called expressive writing, which is the most common kind of writing, kind of a spontaneous stream of consciousness, just get everything out. It's very cathartic in terms of dealing with emotions. Very powerful kind of writing.

But these researchers explored another kind of writing they called peer helping writing where a survivor already having done expressive writing to kind of process their own stuff, now writes as if they're writing a letter to a newly diagnosed patient and offering advice to them based on their own experience.



And in this one little research project, they compared people who did expressive writing with people who did peer helping writing, with people who did both in the sequence of expressive first, and peer helping next. And what they found, at least in this study, is that the only real statistically significant benefits occurred in the group that did the two stages of expressive writing first to kind of process your own emotional reaction and then changing your perspective and doing peer helping writing; now how would I take this and counsel another person about how to get through this? So, the workshop is kind of based on that two-step model.

We'll have different prompts each week at different stages of the cancer journey, but the backbone of it is do expressive writing first, then peer helping writing, and we'll see how that works.

Elissa: That's great. We will definitely have a link in the Show Notes for the LLS Community so patients can get onto there if they aren't already and, hopefully, see some future workshops that they would be able to participate in.

Now I've noticed that you said, the word cancer journey and that gets me into my next question. So, as part of those volunteering opportunities and involvement with the LLS Community, you wrote a recent article titled, "*Language Matters: What Supporters Say is Not Always What People with Cancer Hear.*" Would you tell our listeners more about what is in that article, and why language matters when talking to those affected by cancer?

Steve: Sure. It actually started when I was searching around for a title to that book that I mentioned. As a subtitle, I wanted to use the word journey, cancer journey; you hear that all the time. But as I read these other cancer memoirs, I kept coming across the word journey and it just seemed like it's overused, it's kind of a cliché; but, more importantly, journey implies some things that don't really fit with having cancer. I mean a journey typically is something that we have a role in planning, it's pleasurable, it's fun, it's adventurous; it's a lot of things that having cancer is not.

Elissa: Yeah.

Steve: And so I changed my subtitle from cancer journey to cancer odyssey because that has a whole different kind of implication. It's not something that you necessarily choose, but it's something that can teach you a lot, as Homer learned in the Greek mythology. I also don't like all the militaristic metaphors. "Cancer's a battle. It's a fight. You're a survivor." It's like you're in the ring doing battle. Those metaphors for cancer almost give it too much power. Cancer's not a willful antagonist out to get you. It's just a biological process that does what it does. And so, you almost attribute too much power when you see it as this willful foe and antagonist out to get you.

That's just my reaction. I don't claim it's going to be other peoples' reactions, but it just got me thinking about language and all-

Elissa: Yeah.

Steve: -the connotations. So, I put together a little survey just asking people what kinds of words and phrases they find objectionable. And we circulated it in the LLS Community and in a couple other venues. Got well over 100 responses and so I just spent some time trying to categorize them. And, not surprisingly, the journey thing came in for a lot of criticism. The militaristic metaphors, a lot of people didn't like that. They said, "I have a blood cancer so it's all throughout my body. So if you say I'm fighting my cancer, it really means I'm fighting myself. It doesn't make sense to say I want to do that."

Elissa: Yeah. And you also don't want to go into the almost victim blaming either. It's not the patient's fault-

Steve: Yeah.

Elissa: -if a treatment is not successful. And that goes right in with the battle language-

Steve: Yeah.

Elissa: -that they didn't lose. They aren't the loser. The treatment didn't work.

Steve: You almost exactly reiterated a quote that someone gave about that. The phrase was "You failed your treatment." He said, "I didn't fail the treatment. The treatment failed me."

Elissa: Yes!

Jesse: Yeah!

Steve: Another responder said something to the effect of, "I have Stage IV prostate cancer, so if this is a battle, I know I'm eventually going to lose it. But I prefer not to think of it as a battle I'm going to lose. I prefer to think of it as, I go day by day, carpe diem, but I don't want to think of it as a battle because I'm eventually going to lose it. I don't want to see it that way."

Jesse: Yeah.

Steve: What's interesting about this is not everybody objects to the same thing.

Elissa: Right. It's all different.

Steve: Some people didn't like the term survivor because they said, "We survive all kinds of things in life, so why do we privilege cancer, writing a cancer survivor, but not a divorce survivor or an auto-crash survivor or whatever else-"

Jesse: Yeah.

Steve: -"there might be?" People challenge some rationalizations that can cut both ways depending on both parties involved in the communication. But when people say, "God never gives you anything you can't handle." Well, if you're religious, that might be very reassuring. If you're not, I think it can come across as pretty insulting. One



that was pretty obvious is when someone told someone they had cancer, they said, "Well I guess you needed to learn a lesson." We don't need to go too far on that one. But there's a variety of expressions that, again, what's interesting is they're almost always said with good intentions.

Elissa: Yeah.

Jesse: Yeah.

Steve: But there's just this gap between what the speaker intends and what the listener hears. Rationalizations and comparisons. "At least you have a good kind of cancer that can be easily cured." Well maybe, maybe not. But any sentence that begins with "at least" sounds like a comparison that's going to not honor the experience of the person who's hearing that remark.

Elissa: Right. Now we will post the link to the article, but what is the overall conclusion with this, since you mentioned that all cancer patients will see different words objectionable?

And, even cancer patients talking to ourselves, maybe you might find something objectionable that I like. So, where do we go from here as far as communicating and the words to use?

Steve: I think that's the toughest part of the article.

Elissa: Yes.

Steve: The best thing I could do in the conclusion is say, "First and foremost, we need to respect that different people will hear things differently." And that means, as much as possible, you just need to know the person you're speaking with well enough to anticipate how what you're going to say might be heard. And so generic clichés about "one day at a time" and "be strong", a lot of people just resent that because it's so generic and it doesn't reflect the specificity of who these people are. So, I think if

you can stay attuned to the person, know them as well as you can. Sometimes saying less is better than saying more. Picking up on the cues and how they're hearing it and how they're responding to it and how they're reacting to it, I think is sort of the obligation of people who want to support people with cancer.

Elissa: Yeah.

Steve: But you're right, there's kind of a risk if people read this article. They might say, "Oh man, I better not say anything." And

Elissa: Yeah.

Steve: -that's not-

Jesse: Yeah.

Steve: -where we want to go. But-

Elissa: Right.

Steve: -whatever sensitivity and awareness you can bring to who this particular person is and what will resonate with them. Some people love it when you hear, "Stay strong and go out and fight."

Elissa: Right.

Steve: But I heard someone say, "I don't need that, I just need some empathy."

Jesse: Yeah.

Steve: Or someone else wrote, "I don't need to hear about the guy who runs a marathon on his treadmill every day." It's like there are these heroic figures of people that recover and do these great things. Most cancer patients don't aspire to that.

Elissa: Right.

Steve: They just want to get better.

Jesse: Yeah. To live their lives.

Steve: Yeah.

Elissa: And I think also, in that moment, validating whatever experience that they are having right then. Are they having a bad day? Make them feel validated in it.

Steve: Right.

Elissa: It's okay to not be great all the time and to not be okay. It's okay to have those days, and I think that we can work to validate those experiences and just let them know that you're there for them.

Jesse: Yeah. You said earlier, "Less is more." That's just my motto with everything. I let the person, whatever the situation is, I let them lead that conversation and I try very hard to be empathetic. But I was that person who said those cliché lines and through just natural learning, I'm learning to be more present and be an open ear to that individual-

Steve: Yeah.

Jesse: -and support them however they need to. And that, I think it's very hard to come up with something that's a generalization because everyone is different. So, I think that that advice was very helpful and what I do myself.

Steve: That was, basically, the only conclusion I could come to in the article. I think it's crucial that the patient retain as much control as possible in every facet of their life that they can. And that's why sometimes what people say and the advice that people offer is heard as kind of like an imposition or a prescription for how you should be, how you should get through this. "Let me tell you how to be."

Jesse: Yeah.

Steve: And oftentimes that leads into the whole positive thinking gospel, which I think is very, very double-edged because the insistence that positive thinking is crucial. What do you say about people who don't make it, they weren't positive enough?

Elissa: Yeah. It goes back to the victim blaming.

Steve: Yeah. Another thing in my conclusion was simply avoiding imposing ideas, definitions on other people that don't fit them or that they don't appreciate or that they don't resonate with. And I think, Jesse, your comment about just less is more and find out where they're at, before trying to do something helpful because you're more likely to be helpful if you know where they're at.

Elissa: Definitely. And that's great advice. I hope that everybody listening will go and read your article. That will be linked in the Show Notes.

Now, Steve, for our final question today, on our patient podcast Home Page, we have a quote that says, "After diagnosis comes hope." Based on your cancer experience, how would you finish that sentence, "After diagnosis comes"?

Steve: My variation on hope would be mindfulness, meaning being in the moment, being as nonjudgmental as possible, not fixating on things you can't control, not anticipating the future, not living in the past, staying in that moment.

I've learned to apply mindfulness to what's sometimes called scanxiety, anxiety about an upcoming scan or test.

Obviously, lots of people are subject to that. But it just occurred to me one day. If I get all anxious and bent out of shape because I have some kind of scan coming up two weeks from now, and it turns out fine, I just wasted two weeks of my life worrying about something that didn't even happen.

Elissa: Yeah.

Steve: And if it turns out poorly, that proves that being anxious doesn't prevent a poor outcome.

Elissa: Very true.

Steve: So there, there's no logical case to be made for being anxious.

Jesse: Yeah.

Steve: Now it's easier said than done. But if you can use the, the spirit of mindfulness and being in the moment to tame the anxiety and just wait to see what happens, I mean if you step back, it's crazy to get all bent out of shape about something that hasn't even happened yet.

It might not happen, and it might not happen the way you expect, and the chances are you'll be able to deal with it when it happens.

Elissa: Yeah.

Steve: Especially if you have a solid medical team behind you, which I did. And that made it a lot easier to say, "Take a deep breath, wait till the day of the scan, see what happens, and go from there."

So mindfulness, again, to me just brought this kind of overall hope. Yeah, reasoned hope, rational hope but also a serene calmness and acceptance of where you are at this time.

Jesse: And, Steve, that's also applicable no matter what someone's going through. I think that's great advice.

Elissa: Yeah, absolutely.

Jesse: Why stress about things we don't even know the outcome of? That's for everyone.



Elissa: Well, thank you so very much, Steve, for being here with us today, sharing your AML story, but then also all the wonderful things that you have done for the cancer community and how you continue to be so involved with the cancer community and paying it forward to others. We are so happy that you are still in complete remission over six years later. Thank you, again, for being here today with us.

Steve: Thank you. Thanks for the invitation.

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. In addition to the survey, we are excited to introduce our brand new subscriber lounge where you can gain access to exclusive content, discuss episodes with other listeners, make suggestions for future topics, or share your story to potentially be featured as a future guest. Join for free today at TheBloodline.org/SubscriberLounge.

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

Have you or a loved one been affected by a blood cancer? LLS has many resources available to you: financial support, peer-to-peer connection, nutritional support, and more.

We encourage patients and caregivers to contact our Information Specialists at 1-800-955-4572 or go to LLS.org/PatientSupport.



You can find information about acute myeloid leukemia at [LLS.org/Leukemia](https://lls.org/Leukemia). You can also join the LLS community at [LLS.org/Community](https://lls.org/Community). All of these links will be found in the show notes or at TheBloodline.org

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