

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Support and Stability: Living with CMML'

Description:

Please join us as we speak to Howard Willens, a chronic myelomonocytic leukemia (CMML) patient. In this episode, Howard shares how he was diagnosed with this rare blood cancer. He shares how patient support groups have assisted him, and how he no longer feels alone. His story encourages CMML patients to focus on stability and the present, while living their lives to the fullest.

Transcript:

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

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

Elissa: Today we will be speaking to Howard Willens, a chronic myelomonocytic leukemia, or CMML, patient and retired physician, who spent the majority of his career at the Veterans Administration.

Howard was diagnosed with this very rare blood cancer in June of 2021 at 71 years old. After having abnormal blood tests for several years, he was finally given a diagnosis and has been on watch and wait, or active monitoring, since that time. Howard is now hoping to make the most out of his days while living with CMML by taking up new hobbies like photography and cycling; and is actively looking for a retirement community close to his hematologist or another CMML specialist. Welcome, Howard.

Howard Willens: Thank you for having me, Elissa. It's a pleasure to be here and talk about my experience.

Elissa: Well, we are happy to have you. So, let's start with your diagnosis of CMML. For our listeners, this may sound familiar to chronic myeloid leukemia or CML; but it's actually a different cancer. Howard, could you tell us a little bit about what CMML is?

Howard: CMML is a hematologic or blood disorder that is characterized by overproduction of the monocyte line of white blood cells. It's caused by a mutation in the stem cells or immature cells in the monocyte line so they tend to overproduce and potentially crowd out the other necessary blood cells.

Lizette: Yeah, it's definitely an uncommon blood cancer; and it does have that overlapping feature of the two other types of blood cancer, MDS, which is myelodysplastic syndromes and MPNs, myeloproliferative neoplasms. I know that the World Health Organization (WHO) has actually classified CMML as both, a myelodysplastic and myeloproliferative neoplasm.

Did the doctor say what type of cancer it was to you? I know that we had mentioned in the opening that you are also a physician. So, did the doctor go into how CMML is rare and that it's a type of blood cancer?

Howard: So, the hematologist did go over how it's a type of blood cancer, and he said while it's not common, he didn't really emphasize the fact that it was rare. He did mention that he was following a number of patients with the same disorder.

Lizette: That's a good thing because since it isn't as common, like you said, it's always good to be able to be followed by a specialist with this type of diagnosis.

Howard: Yes. I did want to mention that, for any listeners who were interested, that despite being rare, there is a Facebook page called CMML Friends that has over 1,000 members. I'm part of that Facebook group, and it's been helpful to me.

Elissa: That's wonderful. It's so good to get that support, particularly when you have a rare or uncommon cancer; and we'll get into a little bit later about LLS community and how you got that support there as well.

So, I'm curious, what were your signs and symptoms leading up to this diagnosis? In the introduction, we mentioned that you had been having some abnormal blood tests for a few years. Could you tell us about that?

Howard: I can. I changed doctors when I retired in 2016 at age 65. Prior to that, when my complete blood counts were done annually, they also did differentials; and then they stopped doing the differential or the breakdown of the complete blood count.

In 2019, prior to a surgical procedure, I did have the differential done, which breaks down the white blood cells into its various types – neutrophils, monocytes, eosinophils, and basophils. And it was abnormal, however, neither my doctor or myself either noticed it or paid much attention to it.

Elissa: Was it the monocytes that were off, or were other components of the CBC off?

Howard: No, the complete blood count itself was normal, which is just measuring the total number of white blood cells. It was the makeup of the white blood cells in terms of neutrophils, monocytes, eosinophils, and basophils. The monocytes, both the total number and the percentage they made up of the white blood cells, which I guess physicians call absolute in relative monocyte counts, both of those were elevated. I either didn't notice it because I was going for surgery and had that on my mind or, if I noticed it, I didn't pay it much heed because even though I'm a physician, I didn't know that CMML was an entity until I had it.

Elissa: Right.

Howard: Two years after that I had to undergo another procedure to check my prostate surgery, and this time I again noticed the elevated monocyte counts. Like many laypeople, I went to Dr. Google, and I saw that having persistent elevation of my monocytes for two years most likely meant that I had this chronic myelomonocytic

leukemia, or CMML, which was a new disease for me to learn about. I did not know about it, despite my physician status.

Elissa: Oh wow. Now did you have any signs or symptoms, or was that it really just seeing that the monocytes were elevated?

Howard: I did not have any obvious signs or symptoms. In retrospect looking back, the only thing that possibly was related was an increased frequency of colds or upper respiratory tract infections during the year, although my physician doesn't feel that's related.

Elissa: Um-hmm. I feel like a lot of blood cancer patients can look back and at least kind of see something there that could have been attributed to anything else really besides the cancer, and so then you always kind of wonder was that it? Was that the sign that I missed or was that related? So, very interesting.

Lizette: Right. So, you're saying that you had for two years some bloodwork that wasn't normal and that was it? Because I know that sometimes it takes a long time to diagnose CMML. A lot of times they have to rule out like all the MDS, MPNs, so they have a lot of ruling out to do, so usually it takes a while for patients to get diagnosed. Once you realized this yourself as a physician, did it take a long time to be diagnosed?

Howard: So, for my particular journey, I am part of a hospital system in terms of how I get my healthcare.

I looked up the hematologists who were part of that healthcare system that I belong to, and I selected one and I phoned his office to try to establish; but I was told his primary focus was managing bone marrow transplant procedures and bone marrow transplant patients. They referred me to one of his colleagues, and I've been very happy with that hematologist/oncologist since then.

He put me in very early for a Zoom consult and was somewhat reassuring to me because I was very frightened at that time. He proceeded to do a blood workup that

included genetic markers, chromosome abnormalities, flow cytometry, and, most importantly, a blood smear. And that's how we arrived at the diagnosis.

The process only took a couple of weeks because all the bloodwork was drawn at once, but some of the blood has to be sent to special laboratories where it was processed.

I will tell you that I have not had a bone marrow biopsy. My doctor said that he doubted that it would result in what he called "actionable information." I believe what he meant by that was regardless of the results of the bone marrow, you would be on watch and wait because he believes it's what's happening in the peripheral blood count that drives the need for either bone marrow transplant, cell reduction therapy, or more specific therapy for CMML.

Elissa: You are a physician, so that must have kind of helped this, knowing what the CBC [Complete Blood Count] numbers mean and finding that, again, you had increased monocytes for quite a long time. Do you feel that helped, that you kind of had an idea this is probably CMML and then got to the right person to get that confirmed?

Howard: I'm not sure I know that much more about hematology than a layperson can learn on Google because my focus was in different areas. But I did what I did through Dr. Google and apparently wound up in the right doctor's office. And I've been very pleased with my hematologist/oncologist.

Elissa: That's very good. We never know where we're going to land with Dr. Google. So that is good that you found the right place.

Howard: Your point about Dr. Google is well taken because when you look up CMML, the first thing you read is that it's a terminal disease, with the only hope for cure being a bone marrow transplant, which is a risky procedure and especially risky in someone in my age group.

In the week leading up to the virtual consult with the hematologist, I was quite distraught, to be honest with you, based on what Dr. Google said. And he was somewhat reassuring that the end wasn't around the corner.

So, you're correct, Dr. Google has its pros, and it has its cons.

Elissa: Yeah.

Howard: I'm not sure I did any better than a layperson being a physician, in all honesty, and I'm not sure my responses were any different. It's more the person than the profession I think at this point.

Elissa: Well, I'm glad you finally got to just the right person and you got there probably a lot quicker than other CMML patients. Not that we recommend ever diagnosing yourself on Google. But it did seem to work out for you.

Now I'm curious, your doctor talked about watch and wait. So, after that diagnosis, what was the discussion with your doctor about your treatment plan?

Howard: So, my hematologist and I discussed that the monocyte count, although elevated, was not tremendously elevated or severely elevated. He also mentioned the technical term that there were no reciprocal cytopenias. In layman terms, that means that the monocytes had not yet pushed out the red cell and platelet precursors to the point that I was becoming anemic or a low blood count or having low platelets.

Putting those two facts together, along with the potential side effects of the medications, and certainly the risks of a bone marrow transplant, he advised watch and wait or what he called intense surveillance as the best treatment management strategy.

Elissa: So, what was that like hearing from your doctor that watch and wait or active monitoring, would be the best course of treatment for you at that time? I think when most people think of cancer, we think of immediately going on medication, particularly

chemo. While active monitoring is a treatment course, it just seems a little different sometimes than we might expect. What were your initial thoughts about this?

Howard: I think the most prominent immediate thought was a sense of relief to learn that I did not need to go on these medications and experience their side effects. While there was relief on the one hand, there's always the anxiety hanging over one's head related to when my condition is going to worsen and that feeling of anxiety, at least in my case, is there at some level all the time, despite the fact that I was referred to another great doctor, a cancer psychologist.

Elissa: Oh, a cancer psychologist.

Howard: Yes, I was referred to a cancer psychologist because I believe my hematologist/oncologist could see the anxiety I was experiencing.

Lizette: I think that's actually really good. A lot of our patients that speak to us really have that anxiety. You're not alone, especially for like a watch and wait protocol. And for your hematologist/oncologist to have the insight to be able to say there is a cancer, would you call it psychologist?

Howard: He's a psychologist.

Lizette: I think that's really insightful, and I think that that's really helpful. I know that we've spoken to others on our podcast before in regards to mental health and how important that is for cancer patients; and we often don't talk about mental health. But I think you're right in saying that, you know, it's something that the anxiety is always there. Some people say that you're waiting for that shoe to drop. You don't know when it's going to happen. You don't know when your diagnosis is going to progress, but like you're waiting for it.

And intuitively, you understand that watch and wait is a treatment in itself. It's a point where you may not need that active medication because your blood counts aren't to that level. And I think one thing that you said is really important, you're not having

to deal with right now, those side effects from those medications. And that's really important.

But I just thought that that's really something positive. Were you surprised when your doctor mentioned a cancer psychologist?

Howard: It is very clear to me that my hematologist/oncologist believes in treating the whole patient. And he does his own counseling when I see him for follow-ups. So, I was not surprised that he referred me to a cancer psychologist, and it has been helpful.

Elissa: That's wonderful. And, yeah, I completely agree with Lizette that mental healthcare is so important, and it is treating the whole patient because cancer is traumatic; and you do have other anxieties and fears and everything that come along with that.

So now do you have a plan if your CMML progresses, and your doctor decides that you do need to go on medication or another treatment? Have you discussed this future treatment with your doctor?

Howard: We actually have not spent a lot of time focusing on that, and his emphasis has been on dealing with the present and dealing with my emotional state in the present. I have some familiarity with some of the drugs that are used to palliate CMML, but I haven't discussed them in detail with my hematologist/oncologist. He's waiting for the time when my disease does accelerate before going into all that.

We have discussed bone marrow transplant, and he said that there is a 15% mortality associated with that, maybe higher in my age group, and that it would not be appropriate to do that at this time, since he's seen some patients where the CMML has remained stable for a number of years.

Lizette: Yeah. And even through the course of you being diagnosed, there's newer medications out there that have been approved for CMML. When and if you need

treatment, there are different types of treatments, as you mentioned, transplant, but, also, there's IV, subcutaneous. And now there's actually an oral medication for CMML. Even though this is a small indication, a smaller diagnosis where less people are diagnosed per year, there are still supports for CMML. There's also people doing a lot of clinical trials and coming out with new therapies for CMML. What do you think of that? Just within the last couple of years, a new oral medication is now available so there are different options for you.

Howard: Well, I would agree with you that an oral medication, that I believe is derived from one of the intravenous or subcutaneous medications, represents a major advance. Clearly more convenient for a patient to take an oral medication than to have it administered intravenously in an infusion center or to be giving oneself subcutaneous injections. So, yes, I consider that a positive change, and I'm very pleased or reassured to know that there are so many active investigators out there trying to improve the treatment for CMML and improve the prognosis.

Elissa: Yeah. Just kind of the thought of an oral medication, it seems to me that it would be comforting to know that that is out there that you can kind of still live your life in retirement and do your hobbies while not having to spend two, three days a week or however long in an infusion center.

Howard: Yes, I certainly agree with that and I'm grateful to the scientists and companies that achieved that. And, of course, my hope and prayer is that they'll continue to make progress and even come up with better treatments during the stable phase of my CMML so that when I'm no longer in the stable phase, there'll be even more opportunities for treatments that prolong life.

Lizette: Sure. And just to know that there are those different types, like you mentioned the IV, the sub-Q, the oral, it's actually even something that makes it easier for certain patients to get medication that's covered under their insurance having those many options.

Elissa: Yeah. So, I want to kind of move on a little bit and talk about your life with cancer. We mentioned in the introduction and a couple times throughout the episode so far that you are a retired physician. What went through your head as a physician being diagnosed with cancer? We often hear doctors say that they make the worst patients.

Howard: As far as being one of the worst patients, that would certainly be true in my case. I am absolutely the worst patient in the world, but I work on improving that. Other than that, I would probably say that my response and my feelings are no different than people who are not healthcare professionals. I have taken care of people on chemotherapy, so I know the seriousness of some of the side effects of those medications. But I believe most people have seen relatives or friends on chemotherapy and that I may not have any greater insight into that. I wonder if any of the radiation I experienced in my profession contributed to this.

Lizette: Yeah, it's interesting.

Now, Howard, were you already retired when you were diagnosed? Did it change your plans being diagnosed? I know that you're on watch and wait, but did it change anything for you?

Howard: I had retired only a couple years before the diagnosis. There are feelings of having worked so hard in my career of being robbed of my retirement. It actually did change some plans. I want to move into an active retirement community, and I'm geographically limited because I'm so fond of my wonderful hematologist/oncologist that I don't want to move too far from him. Another thing is I had planned a lot of traveling in Europe, and I'm hesitant to take long plane flights frequently because there is a little bit of radiation exposure with air travel, so it did change some of my plans. On the other hand, I still try to live every day as much as I can and enjoy what I'm doing locally.

Elissa: That's good. Now regarding the radiation for long plane travel, have you discussed that with your doctor about those concerns?

Howard: As I mentioned, I am holding the crown for world's worst patient. I have discussed it with him, and he said I shouldn't have those concerns, so he's really a wonderful doctor. And that's probably more scientifically accurate than my superstitions.

Elissa: Yeah. Well, it's something to think about, although we are still in the age of COVID, so there's that little bit extra risk there. But hopefully, we'll not be in this forever and maybe by the time we get out of this and it's a little safer that maybe something that you can do. I'm a big proponent of going to Europe and also living your life. And I'm glad that you found some hobbies like cycling and photography. That must be still pretty fulfilling for you.

Howard: I wouldn't say I'm a very good photographer, but I'm better than when I started. I do belong to a camera club, which is very fulfilling. I've made some friends within the club, although it's all by Zoom and telephone right now. And I hadn't bicycled since I was about 10, and realizing how much fun it is, I wish I hadn't given it up at age 10 to do what seemed to be more competitive sports at that time. But I'm not an offroad cyclist. I just pedal around my community and local areas, but I enjoy it.

Elissa: And that sounds perfect. As long as you enjoy it and you find a way to enjoy your life, it doesn't matter how good you are. What matters is that you enjoy it.

Now you mentioned a little bit earlier about support that you've gotten from your Facebook group and then we were initially connected to you through our LLS Community, which is an online gathering place for patients, caregivers, and healthcare professionals to share experiences and provide support. What made you want to join that, and do you feel like it's been helpful with connecting with other patients?

Howard: I believe, as I mentioned, I was somewhat distraught during the first few months of my diagnosis. At the cancer center where I see my hematologist/oncologist, they had a list of support groups on the wall, and I asked them to give me a xerox copy of that. The LLS Community was one of those support groups, and I joined, and it's been wonderfully helpful. I think it's a great organization. I believe the group I frequent most on that website is called the rare leukemia group.

Elissa: Okay.

Howard: That's where CMML patients are embedded, and I've made some contacts there. Found out a little bit about patient courses with their disease and, in fact, one of the members I contacted on the rare leukemia subset of the LLS Community is the one who connected me with the CMML Friends Facebook page.

Elissa: Great. Yeah, the more ways that you can get support I think the better.

Howard: I do the transplant group monthly through LLS, and I've seen some other presentations. I was able to pose some questions on the LLS Community about my disorder, CMML, and they were kind and gracious enough to connect me to perhaps the world's leading expert based out of the Mayo Clinic.

Elissa: Wow!

Howard: And he gave a comprehensive presentation on the site.

Elissa: Oh, that's so great. We put on educational programs because that's really what it's all about. We need to be able to educate you about your disease and when it's a more rare disease, we really want to make sure that you're getting accurate information all the time and also being presented with options. Even though you're on watch and wait, there are other options out there for when your disease does progress and it's good for you to know about that and be educated about it.

Howard: I would agree. The LLS Community is just wonderful for education.

Elissa: So, one last question for you, Howard. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your cancer experience, what word would you use to complete that sentence, "After diagnosis comes"?

Howard: I don't think I can come up with a better word than hope to be honest with you. I think that's the perfect word.

Elissa: What does that mean to you?

Howard: What that means to me is that there is still an opportunity to live even in the face of a diagnosis such as CMML.

Elissa: Absolutely. That's a great way to end our podcast that there is hope to live. Thank you so much, Howard, for joining us today. I think that this was really insightful about such a rare leukemia and so I hope that all CMML patients and their families who are listening today will get a really good insight and also find that connection with you. We will have the information about LLS Community for any of our patients/caregivers who would like to join that and maybe they can say hi. So, again, thank you so very much, Howard, for being here with us today.

Howard: Thank you very much for having me.

Elissa: And thank you to everyone listening today. *The Bloodline with LLS* is one part of the mission of The Leukemia & Lymphoma Society to improve the quality of lives of patients and their families.

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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 also find more information on CMML at LLS.org/Leukemia and our LLS Community at LLS.org/Community. 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.