

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Improving Quality of Life Through Wellness Practices'

Description:

Join us as we speak to Heidi MacAlpine, a chronic lymphocytic leukemia (CLL) patient and occupational therapist. In this episode, Heidi talks to us about her diagnosis of CLL and how she has utilized wellness techniques to reduce inflammation and maintain a good quality of life while on a watch and wait protocol.

This episode will help patients, caregivers and healthcare professionals understand the benefits of adding wellness practices to conventional therapies, such as yoga, mindfulness, journaling, and massage, to decrease side effects and improve the life of patients following a cancer diagnosis.

Transcript:

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

Jesse: I'm Jesse.

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

Elissa: Today we will be speaking to Heidi MacAlpine, a chronic lymphocytic leukemia, or CLL, patient and licensed Occupational Therapist. Heidi owns a wellness clinic in New York where she specializes in Yoga, mindfulness, and myofascial release. These complementary therapies have greatly assisted her in her wellness journey after being diagnosed with CLL in 2019. As a Yoga therapist, personal trainer, and certified trauma practitioner, Heidi loves to empower and support her fellow cancer patients by sharing how wellness programs and interventions can be integrated with their conventional medicine treatments to improve quality of life and decrease side effects.

Welcome, Heidi.

Heidi MacAlpine, OTD, M.Ed., OTR/L: Pleasure to be here. Thank you for inviting me.

Elissa: Thank you for joining us. Well let's start with your diagnosis of chronic lymphocytic leukemia, or CLL. What were your signs and symptoms leading up to your diagnosis, and how did you end up getting diagnosed?

Heidi: It was a fluke that I got diagnosed with the CLL. I worked with children in early intervention. I contracted the parvovirus.

Elissa: Oh!

Heidi: And from the parvovirus, I got a lot of inflammation in my hands and feet, and it limited my ability to function and perform everyday activities independently. So, I went to my physician to figure out what was going on. Initially, I thought it was Lyme disease, but upon further testing, blood tests, they determined that my Epstein-Barr virus was heightened, my parvovirus markers were up, and then they had considered some other things and they wanted me to see another practitioner to see if maybe it was Lupus.

So, I did originally get diagnosed with Lupus. I did not want to go on the medicine. I did not like the side effects, so I thought that I would work on healing myself. But, as the doctor recommended to take the medicine to see how things worked out and, also, because I had a blood clotting factor as a result. So he goes, "Do you want to have a stroke? Do you want to have a heart attack as a result of your blood clotting factor?" So that made me think about it, and I said, "Let me take the medicine. Let me work with all the complementary therapies that I've utilized and see what happens."

I went on the medicine for a year. And within a year, my markers were gone for Lupus, but there was one little marker there that he wanted me to get checked out by cancer specialists just to rule out anything. They found that I had the marker for CLL.



And it was very minimal, they would never have found it because I did not have symptoms of just CLL.

So, that was my journey. But through all of my journey with my autoimmune diseases, I wound up researching. As a healthcare professional, I wanted to research and gain data on different diagnoses and what worked and what didn't work. So, I wound up using my Yoga, my myofascial release techniques, and essential oils to help work with my stress levels, decrease inflammation, increase range of motion, and increase my energy levels. And it did happen.

Because they don't have answers right away, they're looking for all of the bloodwork, so, within that process of waiting, I wound up doing my own therapy, and it helped. It decreased the inflammation. It increased my ability to function independently, such as dressing. I could not dress myself. I could not drive because I couldn't grip the steering wheel. That being said, I have an idea of where CLL could go.

My mother was diagnosed with it many years ago. She passed away when she was 60. That was 30 years ago. So, I have the same diagnosis as my mom did then, and I know where it goes. I know the symptoms, I know the challenges, I know the ups and downs of having a diagnosis of leukemia.

I really wanted to be proactive. I don't want to wait for symptoms. I want to be proactive, and I teach my clients in all populations how to be proactive with these tools that I've utilized, and I share my story.

Jesse: After your diagnosis, Heidi, what was the treatment or treatments that your doctor discussed with you?

Heidi: So, after my diagnosis, the doctor knew my history, knew that my mom had a history and that she had passed, so, she wanted to know if I had any questions regarding the progression of it at some point. But they weren't as concerned and didn't feel like they had to go into options yet because it was so minimal, and I wasn't

required to have treatment yet. It was just being monitored and making sure that my blood levels didn't elevate.

Lizette: Yeah. And there really can be a lot of misunderstanding when patients are told do watch and wait versus taking a medication, taking a treatment. Did your doctors explain to you watch and wait? I know that you said that you understood the disease because your mother had it. But watch and wait is sometimes difficult to process after you're told that you have a cancer diagnosis.

How did you feel when you were told that you were going to be in watch and wait or active monitoring because it's still a treatment, to monitor you.

Heidi: Yes. And to monitor my own health is a treatment in itself. Just as you're saying that it's like posttraumatic stress. My heart rate started increasing. I remember that day. I remember it very clearly, and I remember where my thoughts went. They weren't good thoughts.

Lizette: Right.

Heidi: They were fearful thoughts. They were thoughts that wouldn't help me, but I had to go through that process, and I had to be proactive in my internal thinking and thoughts. It was scary. It was a very scary place to be. I did cry, but I have to talk to people. I'm not someone that just waits for days and process, I have to share it. So, I had a support system, which I think is important, and I notice that you have the journaling for the support system for the patients, but also the caregivers and that's important, too, because my husband went through his own process.

He went through that with my mom with me when we were initially married and everything that she went through, and the hospitalizations and the in and out of the hospitals. So, he knew what that meant according to what we knew.

Lizette: Right.

Heidi: And I could read all that I wanted to, but it was really my past experience that I had to work through. Then say to myself, "What can I do today? And not worry about the past, not think about the future." It really was being in the moment. And that's what a lot of my treatments are, and complementary therapies work with.

Lizette: Sure. And since your mother did have a diagnosis and you knew that it was a chronic diagnosis. So, a chronic diagnosis, right now there's management for the disease, but there's no cure. Like you said, your mother was in and out of treatment and in and out of the hospital. How is that for you, that it's a chronic type of leukemia, that it's something that will kind of ebb and flow for you?

Heidi: As of today, that's what I'm focusing on, it's good. It's not going to define me today. And I think that's what happens when you're working with patients and you're giving them a diagnosis. It's not the everything for today.

Lizette: Sure.

Heidi: And I can't worry about what could be, because that could put me in a whole different state of mind. It could change my whole physiology because of the way I'm thinking. So, I think body and mind have to work together and there has to be a balance. My business is called W.E.L.L. Alignment for a reason. The W.E.L.L. stands for Worldly Empowerment Living and Learning, so we're going to learn together as a group.

Lizette: That's great. I want to point out that there has been some studies that there is more of a hereditary link within CLL. I don't know if your doctor pointed that out as well as, that at this point, there are so many new treatments for CLL. So, if you talked about that your journey is going to look very different, everybody's journey is different. I just wanted to ask if the doctor really talked to you about the newer treatments and let you know that the way that CLL is treated now is different than when your mother was treated with CLL.

Heidi: Yes. It was touched upon. I don't think the time was there to really go over specifics. We had a good rapport, and she knew what I was doing, and what she said to me is, "Do what you are doing. Keep on doing that because it seems to be working."

It was through my own education and research that I gained insight into the different treatments and the possibilities and where it could go and what my options were.

Elissa: Now, one thing we hear from many CLL patients about watch and wait is that it can feel like they're constantly waiting for the other shoe to drop, "When will my disease progress to where I need medication? How will the medication affect me? Will it work?"

We mentioned in the introduction that you are an occupational therapist, and you talked a little bit about your business, and you do complementary wellness.

We're going to get a little bit more into what that is in a moment, but, first, you mentioned earlier that some of the therapies have helped you personally, particularly with the inflammation while you're waiting for all the testing. Have you continued to do those after your diagnosis, and could you go a little bit more into those therapies in-depth to share how they helped you?

Heidi: It's my own self-care. It's what I did, to a certain degree, before the diagnosis but now I understand the importance of consistency with utilizing those different types of therapies. I go for massages, I do myofascial release, which is a form of massage; just a little bit different. I do reflexology. I practice Yoga. I do mindfulness. I work on breathing and being in the moment, centering myself, focusing on what's good, what's positive, what's working and not what's not working because I don't want barriers to me enjoying life today.

I've used all of those, and I'm consistent when I utilize them. I find ways to make money so that I can do those things because I know there are health disparities with



different populations who cannot afford that complementary type of therapy, so I like to offer it on a sliding scale.

I also like to do community-based groups for free, at different sites so that they better understand the differences of how it would feel to get this complementary therapy. So, it's really empowerment. It's giving them knowledge and providing them with opportunities to better understand what is available. I don't always think that it is introduced in that way, but they are evidence-based practices.

And I think a lot of times that's what physicians forget about. I am a healthcare provider, so I do need to look at their diagnoses and any contraindications. I do that thoroughly. With Yoga therapy, we do get a doctor's referral. We do have an intake form. We do have waivers that they sign to let us know what issues they're having.

I think it's important to be aware of the client and where they are and what their barriers are and their challenges and how the diagnosis can be utilized with a different complementary therapy.

Elissa: Wow, that's great. It's so good to hear that, you've not only helped yourself but you're really working to help your community. And I love, too, to hear that this is evidence-based medicine. It is evidence-based wellness, and so you can look into how these are truly helping people. That's just wonderful.

Heidi: Right. And I think a great website to look at is the National Institute of Health for Complementary [and Integrative Health] Therapies, and they give you all that data. They give you the research behind it and it's fact based, so then you can make your own decision as a patient if it's something you want to try or not.

And always staying in communication with your physician and your doctor. It's important so that you're working together, and they can help you through that process.

Elissa: Yes. It is part of what we love to talk about here is shared decision-making. Working with your doctor to come up with the best treatment for you.

Heidi: Right.

Elissa: This can be very much part of your treatment, getting medication or active monitoring, and then doing this to help with stress, side effects, and just general quality of life.

Heidi: Right. And I know according to the American Association for Cancer Research, one of the gaps is providing interdisciplinary research and then carrying it into practice, so to gain more data on the benefits of these different programs. So, I think that's something that the clients can look up, too, just what's going on with cancer research and how we're working with the different gaps in cancer treatment.

Elissa: Absolutely.

Lizette: Let's take a step back and discuss what occupational therapy is. Could you please share with our listeners the benefits of occupational therapy and what it entails?

Heidi: Okay, that's a big question, but I'm going to simplify it. Occupational therapy works with all populations, age ranges, and communities. And we are looking at the whole person, so I think that's where I was coming from, looking at the person's physical, emotional, spiritual, and social aspects of life. And so, part of that, and I'm going to relate it to my cancer diagnosis, is the support that I received as a result, and that's part of the social aspect, sharing your experiences, providing information.

The emotional aspect is working with the internal parts of the person, the aspects that may create even more barriers to learning and gaining all those things that you need to progress along with your journey of being diagnosed.

And that is just your attitude, working through your fear and fears can immobilize us. So, there's that fight, flight, or freeze state for a trauma. And a trauma is getting a

diagnosis. It doesn't have to be this big thing. It doesn't have to just be a car accident or trauma from war. It can be gaining a diagnosis and wondering what to do with that because it is a scary place to be.

So, how do we get out of that state? Do we not think about it and flight? Do we fight? Are we angry? Do we create animosity within our own family structure as a result of that diagnosis? Do we freeze? Do we become depressed? Do we just stay isolated? And that's what happened during COVID with people who had diagnoses and with older populations, is they became isolated. They didn't have that support system. They weren't talking about what was going on with them. I think working past the fight, flight, or freeze response and living in the moment.

Lizette: Right. A lot of times people don't know what occupational therapy is.

Heidi: So, it's working with function. Not only are we working with strengthening range of motion, we're working with activities of daily living. But also, what is an occupation? An occupation is something that you love, need, and want to do. Whatever that might be. It could be a leisure activity. So, you're a senior with a diagnosis and you love going to the senior center, but either that diagnosis has created fear and you stay home as you're processing that information, or you are getting treatments and you're dealing with the side effects.

How do you still do the things that you love, need, and want to do? Whether it's your activities of daily living, so is that self-care? Is it cleaning your house? So, looking at who that person was prior to their diagnosis, what were the occupations that they were engaged in, and how can we get past those barriers and challenges so that you still do the things that you love, need, and want to do?

For a child, it's school, maybe school age. It's functioning in school, performing your homework, performing being a part of school, making friends. As a teenager, it's social networking, being in groups and how to be a good teammate.

With an older population, it could be volunteering, leisure activity, socializing with your church group. It's the physical aspect of someone, it's their emotional, it's their social. So, it's looking at the whole person and helping them to function in everyday life.

In my role, I do community-based programs now to be able to work with social groups. I work with kids with autism so that they do learn social skills and that they are a part of society, that they are part of a community, working with their physical aspects, their coordination, their strength, range of motion. Their emotional piece, working with their fight or flight, working with their ability to deal with everyday challenges in a proactive way.

Elissa: I love that one of the things that you mentioned was, not only the physical aspects of an injury or illness, which is typical for occupational therapists to deal with, but the trauma that comes with cancer, that comes with a cancer diagnosis, comes with treatment.

We deal with triggers that come up and sometimes it is hard to move back into just daily life, the things that we love to do. You might get triggered by the things that you love to do prior to your diagnosis. So, I think that's a really important thing that you brought up that it isn't just dealing with the activities of daily living.

Heidi: Yeah. No, there's just so many different aspects to a person and they all go through their challenges differently because they're all unique in how they cope. I do a lot of coping strategies and then relate it to an activity, so it's always activity based when we're working as an occupational therapist.

Lizette: Right. And as you're mentioning, those activities of daily living and, relearning how to do those activities. Now why did you choose to focus on wellness, in particular, in your practice?

Heidi: Well, it started with my own wellness. I'm my own case study, and I have the data to support my health. I went from being monitored every six months to now

yearly. So that says a lot to me that I'm being proactive, and I'm working to the best of my ability to make sure that I maintain my health for my children, for my husband, for my grandchild, for the people in the community that depend on me. That's why I did my own wellness for my own stress management. The more I worked and the more children I had, the more stressful it became. And the only one who's responsible for my health is myself.

Elissa: Let's discuss some of the programs and interventions that you use. Now we mentioned in the introduction, Yoga, mindfulness, and myofascial release. You brought it up a little bit earlier, but I want to go a little more into it. So, while the first two may be familiar to many, I'm not sure many will recognize the last, myofascial release. Could you explain myofascial release to our listeners and how that is beneficial?

Heidi: I would love to. I would love the opportunity to help everyone understand that it is a noninvasive technique. It works with the connective tissue, that's intracellular, that's bone to muscle, that's muscle to muscle, that connects us, is fascia. It's a sheath. So, if you can imagine pulling the skin of a chicken off and seeing that sheer sheath that is on top of the muscle, that is fascia, but fascia goes deeper.

You get a regular massage, and it works on the surface. It works with that fascia just below the skin. But when you do myofascial release, you are waiting at the barrier. Usually, people come to me because there's a physical limitation that they no longer can deal with, and they want relief immediately because they want to function in everyday life and now it's becoming an issue. It's becoming a barrier to that.

So, they come with me with these physical issues but what happens is when they're releasing these physical issues. When I'm performing myofascial release, an emotional component is connected to it. It's that fight flight or freeze. With every stressor, there's an emotion that's connected to it. And it's usually fear, anxiety, and all of those things that are created as a result of whatever occurred within your life.



So, the emotional I have seen is connected to the physical. Once we work at that barrier and they're breathing, I'm guiding them through breathing and relaxing and letting go, I go deeper. I follow the body; I'm connected to their body. It's not forceful because once you create force, when you've gotten a massage and it's a little bit too hard, your body goes into freeze. It like automatically tightens up, and that's what we don't want. So myofascial release is an hour to an hour and a half.

We can wait at that barrier for three to five minutes and then release it because we're waiting for the body and the fascia to release and lengthen at different levels. It's like unpeeling an onion, we're going deeper and deeper, and I'm breathing with you, we're connected, we're releasing that tight energy which increases the lengthening.

It's increasing oxygen to the cells which now creates blood flow, and the blood flow now creates heat and heat releases that restriction even more, so now you've got more lengthened tendon and muscle, and then you're releasing and you're becoming more functional as a result.

I don't know if you've ever heard of referred pain. So, somebody says, "Oh, I got a pain in my hip." And then when I'm working and I'm assessing the body, I realize that there's tightness in the neck and it could be on the opposite side creating pressure. And as I release that area in the neck, they go, "Oh my hip is feeling better now, but I feel that in my left toe." The fascia connects everything.

You could've had an injury when you went skiing at 12 and then you had an injury on a motorcycle accident, or an injury falling off a ladder, or an injury just falling on ice that compounded that restriction. So, it constricted the blood flow, now you have tightness and then you have pain. Because people can deal with tightness. They think, "oh, it'll go away." Sometimes it doesn't. It tightens and restricts and stays in that until you get stressed and then it tightens it even more.

It's longer. It's not just a quick massage over the area. You're staying within that restriction for three to five minutes until it releases and goes deeper and then you



release the restriction completely. And sometimes it takes more than one session depending on the different areas that have been affected by injuries.

Elissa: Yeah.

Jesse: With the programs we just mentioned and others that you do, how do these help cancer patients with quality of life or side effects?

Heidi: Great question. I hope I can answer that as concise as possible. So, we talked about the mind/body connection and really working with the emotional piece getting past that fear. It's creating barriers for living in the moment and enjoying your life after diagnosis.

So, if you could start early with support groups that help do that, with stress management groups, then you're decreasing your chances of increasing inflammation and limited range of motion and creating barriers to doing the things that you love, need, and want to do. Which are occupations that you engage in every day.

The emotional affects the physical and then by working on the physical, so if you do the myofascial release and the Yoga, you're connecting the breath with the movement and the releasing of restriction so that you can do the things that you love, need, and want to do.

Myofascial release helps with lymphatic drainage because you're working with the immune system interleukin; I think it's interleukin 8 for the white blood cells to help fight infection. You're increasing those to fight infection by working on the emotional and physical and managing your stress levels.

Jesse: Very good. Thank you.

Lizette: We've mentioned a few times the term complementary wellness. So, this can be confusing for patients. It can sound similar to alternative medicine. Could you



just explain the difference of how complementary wellness can be used alongside the conventional treatments given by your oncologist?

Heidi: Great question, and it's in the wording, complementary. It complements your present protocol. So, it complements to help work with your health, wellness, and your quality of life.

As a healthcare professional, I'm working interdisciplinary with other professionals like PT (physical therapy), social work, the doctor, the physician, to gain an understanding of that client and the different aspects.

The client may be saying one thing to one person and then another thing to another professional, so you really want to collaborate and provide this program that complements what's already existing to help work with health and wellness and quality of life.

And maybe integrative doesn't have as much evidence behind it, where complementary would have more evidence-based data to support the utilization of it with certain populations and communities.

Elissa: So, speaking of evidence-based data, in addition to patients and caregivers, healthcare professionals also listen to our program. What would you say to healthcare professionals on how complementary wellness programs and interventions can assist their patients throughout their treatment and into posttreatment survivorship?

Heidi: We look at the data and there's great research behind the American Association for Cancer Research. It talks about disparities. It actually is more qualitative data, so it's looking at the client's experience because really that's what we want to try to work with. What's a client experiencing? What are their barriers? What are their challenges? What are their strengths? So not even just coming from a disease or a disability approach, it's more from a strength-based approach.

So maybe they were a Yoga instructor, and I'll give an example. I worked in an assisted living facility over COVID, and we performed Yoga groups. We did mindfulness groups. And one of the residents there had been a Yoga teacher prior to going into assisted living. So, we had them work with us and come up with groups and lead some groups because what's better than having another person who understands what you're going through.

Elissa: Right.

Heidi: I think there's more community-based programs that need to be available to clients.

Elissa: Yeah.

Heidi: I think the journaling is great. What do you do with that now? What's the activity that you do after the journaling? An occupational therapist could run groups based on that journaling. Have them share, have them do activities, have them get involved in leisure activities and looking at each member of the group's strengths. So maybe they can't write. Maybe they don't have enough energy to really participate to the degree that they want to. Well, how can they participate to feel value where they are today? We all have value regardless of where we are in the journey.

Elissa: Absolutely.

Heidi: These community-based groups would be great for other healthcare professionals to start getting involved in. Looking at the whole person, looking at who they were prior to their diagnosis, and really, as an occupational therapist, we do an occupational profile which really identifies all of that. It's a checklist, "So what did you do prior? What are your strengths? What are your challenges?" All of those come into play to help formulate groups, to help formulate interventions that are client centered. And more research. We need more research to support and fill these gaps.

Elissa: Yes. Yes. I think that's a great idea to get more people doing it and get more research there. And for those who are wondering about the journal that you mentioned, we will have a link in the Show Notes so that you can get a journal for yourself or if you're a caregiver listening, please get that.

For our last question today, on our patient podcast Home Page, we have a quote that says, "After diagnosis comes hope." Based on your experience as a CLL patient and a wellness practitioner, what advice would you give to patients and their families following a diagnosis of cancer?

Heidi: Hope's a big word when you're in that space of doubt and that darker space that pulls you down. So, I think giving them the okay to be in that space. It's okay to be there and process, make sense of it and shut out parts of the world that are loud and very sensory overwhelming.

I know people that have been exposed to trauma. Even the things that we take for granted like a bird singing or a vacuum going, all those things are overwhelming when somebody's in that space. So, allowing them that space and then just listening.

Elissa: That's perfect. Well thank you so very much, Heidi, for joining us today and sharing all about these wellness therapies that can really help people alongside their conventional treatments and help them with their side effects, help them get through the cancer experience just maybe a little bit easier than they would without it.

We really appreciate you being here and sharing your story and I'm so glad to hear that you are helping your local community in such wonderful, beautiful ways, so thank you again.

Heidi: Well, thank you. It's been a pleasure.

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 announce 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.

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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 chronic lymphocytic leukemia (CLL) at 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.