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THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

# *Episode: 'Live at IWMF: Living with Waldenström Macroglobulinemia'*

## Description:

For patients with chronic blood cancers, such as Waldenström Macroglobulinemia (WM), quality of life is a main priority. Physical and emotional side effects of the disease or treatment may present several challenges for patients and caregivers.

In this episode, we were onsite at the International Waldenström's Macroglobulinemia Foundation's 2024 IWMF Educational Forum in Renton, WA. Elissa met with experts who discussed how integrative oncology, wellness, mental health, and peripheral neuropathy affects WM patients and their caregivers.

## Transcript:

**Elissa:** Welcome to *The Bloodline with LLS*. My name is Elissa, and today we are podcasting live from the 29th Annual IWMF Educational Forum, a conference put on by the International Waldenström's Macroglobulinemia Foundation. This year, the conference is taking place in Renton, Washington, and is attended by cancer patients, survivors, caregivers, and healthcare professionals. LLS is a proud sponsor and exhibitor at this annual event.

Waldenström macroglobulinemia is a rare and typically slow growing type of non-Hodgkin lymphoma that affects the white blood cells. Each year, patients, survivors, and caregivers come from around the world to be educated on the latest advances in treatment and the management of side effects. In this episode, we will be hearing from some presenters at the IWMF educational forum about the highlights of their presentations on wellness, peripheral neuropathy, and integrative oncology. So, let's get started.

***Integrative Oncology***

**Alissa Huston, MD:** Alissa Huston. I'm co-Medical Director of the Pluta Integrative Oncology and Wellness Center, which is part of the University of Rochester Medical Center, Wilmot Cancer Institute, and I'm Associate Professor of Hematology/Oncology.

**Elissa:** That is in New York?

**Dr. Huston:** That is in Rochester, New York.

**Elissa:** What was the name of your session, and why was it important for you to present on this subject, particularly for Waldenström's patients?

**Dr. Huston:** So, my session was on optimizing quality of life with integrative oncology; and it was important because we've seen such a growth of the research behind and driving integrative oncology modalities. And I think it's so important for oncology patients to be able to understand where these different interventions can help support symptoms, which many Waldenström's patients face, whether it's from the cancer itself or from the treatments that they're undergoing.

I think also in Waldenström's, there's this long time frame where patients may or may not be initially on active treatment; but what are other ways that they can implement certain lifestyle modifications, exercise, nutrition that can really help prepare them for when they have treatment? We call that pre-habilitating.

**Elissa:** Yes.

**Dr. Huston:** And so, trying to talk about those tools and the research really behind those tools.

**Elissa:** Okay. Now, you mentioned in your presentation four areas of integrative oncology. Could you go over those?

**Dr. Huston:** Yes, so there's many different facets of integrative oncology. We look at movement, touch, nutrition, and mind-body practices.

**Elissa:** Okay.

**Dr. Huston:** So, we really focus on those interventions. And tying it all together is often meeting with an integrative oncology provider to really help focus in on what the goals and objectives are, what is important to the individual, and how we can pull in, again, looking at the evidence, the recent guidelines that have been published from our joint organizations, ASCO (American Society of Clinical Oncology) and SIO (Society for Integrative Oncology), or what the National Comprehensive Cancer Network (NCCN) says about what the strength of the evidence is for inclusion of different modalities.

**Elissa:** So, what are some examples within those four areas that you had just mentioned?

**Dr. Huston:** Right, so under movement, for cancer-related fatigue that so many patients can experience. Again, we think about Waldenström's. Anemia or treatment-related fatigue. Exercise has high levels of evidence and research that's been done to support its use and is a part of a first-line recommendation per NCCN (National Comprehensive Cancer Network).

**Elissa:** Yeah. And exercise, in particular, it almost seems counterproductive, right, when you're-

**Dr. Huston:** It does.

**Elissa:** -talking about fatigue.

**Dr. Huston:** Yeah.

**Elissa:** And it's like, wait, you want me to exercise when I can barely get out of bed.

**Dr. Huston**: We talk about this all the time with patients. It seems so counterproductive, and yet it has the strongest evidence. It outperforms all other modalities to help with cancer-related fatigue.

I think part of that is thinking about how do you engage in that exercise earlier? How do you incorporate it in and having that support? So, in our center, we have a wonderful program that's been developed by a colleague at the center. Dr. Karen Mustian created this ReNEW program, and that is specific for our oncology patients. So, there's oversight from an exercise physiologist that has oncology training that can really help guide patients.

The other thing I'll put a plug in is that the new fatigue guidelines, that's another SIO-ASCO joint guideline, is going to be published at this coming ASCO. So, it's exciting to see what additional recommendations there are, specifically with cancer-related fatigue, as we were just talking about.

**Elissa**: Oh, that's really interesting. So, then the other ones, there was touch.

**Dr. Huston**: Touch. So an example in touch would be acupuncture for chemotherapy-induced neuropathy, which so many patients face. Again, most of the research is in neuropathy from chemotherapy, although we know that, again, thinking about specifically Waldenström's patients, they can develop neuropathy from the Waldenström's itself, from that monoclonal spike that can impact and cause that neuropathy symptoms.

But, what are ways that we can support, and acupuncture would be one of those. That there's part of our National Comprehensive Cancer Network guidelines that it can help with neuropathy symptoms.

**Elissa**: Okay, so we have movement and touch and what's next?

**Dr. Huston**: So, nutrition. We know that there's strong evidence that nutrition can help throughout all aspects starting from initial diagnosis. It has been shown more plant-forward diet to help lower mortality for cancer survivors. And thinking about Waldenström's patients, who live for years, it was wonderful to see this morning looking at the decades as patients were standing of how long they've had Waldenström's. So, how do you help keep patients healthy and well and impact their risks of cancer returning or progression over time? So, there's strong evidence that a more Mediterranean-based diet can help lower mortality when you adhere to it.

And then the last one is mindfulness, mind-body interventions. So, the one I'll pull from that is yoga; and yoga has a lot of research. IWMF has a wonderful yoga therapist that has a program that they run with online classes, and some different educational programs and webinars. Yoga can help with mood. There's evidence that it can help with anxiety and depression during and after treatment. That was part of the SIO-ASCO guideline that just came out this past fall that yoga had benefit in those areas in both pre- and post-treatment for patients.

Along with that, meditation and mindfulness also had very strong evidence to help with anxiety and depression, both during and after treatment.

**Elissa**: Wow.

**Dr. Huston**: Yeah, so these are all tools that patients can utilize, can call on, can learn to do and incorporate in, alongside their conventional cancer care, like incorporated with it, integrated right within it.

**Elissa**: And that brings up the point that you made about definitions and alternatives because we've all heard of alternative treatments, and I think patients can automatically go to that mindset, that these are alternative treatments instead of whatever their doctor is recommending – the chemotherapy, radiation, whatever it is – versus complementary or integrative. Could you explain all that?

**Dr. Huston**: Yes. I always think it's really important to make a distinction. So, alternative, which you're right, a lot of people use that nomenclature and say, "Oh, I'm doing an alternative treatment." Really what that means, by definition, is that it's something that's being done in place of conventional cancer care.

That's not what integrative oncology is. What integrative oncology is, is really integrating these different modalities that focus on your mind-body practices, lifestyle interventions, but really weaving in these evidence-based interventions within and alongside that conventional cancer care.

Then complementary is doing them in tandem almost, but integrative is really weaving them together. So, you're doing these things, but you're doing both of them, which I think is really critical that you're not doing just an integrative intervention and not the recommended care for your cancer.

**Elissa:** And so, patients are then actively working with their treatment team then to get these integrative modalities started?

**Dr. Huston:** Yes. For example, in our center, we have yoga therapists. We have a meditation provider. We have oncology massage therapists, two acupuncturists. So, we have all of these different providers; and patients will meet with them to receive that care based upon what their symptom is, what that recommendation is.

There's also a lot of community partnerships that occur. The example I often give is the YMCA and Livestrong, if you're looking at incorporating an exercise program, because that's geared towards oncology patients. So, that's a way of engaging within the community.

The one point that I always like to make though is that you want to make sure that those providers have additional oncology understanding or training. Many of the different modalities do have oncology training. So, for yoga, for acupuncture, for massage, there's training that can be done. I think that's really important, because as a cancer patient, you want to make sure that your provider understands the different nuances of your cancer, what your blood counts are, do they need to be more concerned about infection risk because of what you're undergoing? And that comes with that additional training.

**Elissa:** Okay. Now patients listening who may not have an integrative oncology clinic at their hospital, what is your advice for them to still be able to get these types of care?

**Dr. Huston:** Yes, so there are a lot of different community-based providers, although I really would look to see kind of what that person's certification is and what training they may have done to make sure that you're going to someone that's really going to make those evidence-based recommendations because that's really important, like with anything. When we're thinking about treatments, we look to what the research and evidence shows. So, we should be doing the same thing if we're recommending acupuncture or yoga or massage or even exercise. We should be looking at those recommendations.

So, I would say, looking at what resources there are in your community, maybe talking with your provider to say, "Look, I'm interested in these. Can you help or identify?" and hopefully you have a provider that's open and that maybe can point you towards certain resources locally.

And then, certainly there's different online resources that you may be able to look up and review as well that are either through a large academic cancer center or maybe someone's near a large academic cancer center where they can look to see. I know that say Memorial Sloan Kettering has done a lot of virtual opportunities where patients can participate in different ways. Maybe it involves a little coordination. But you may be able to also find some additional resources.

**Elissa:** Okay. So, we've talked about quite a lot of things now. With these studies being done, what is the real benefit of all of these modalities for patients either undergoing treatment or into long-term survivorship?

**Dr. Huston**: So, I think that there is definitely evidence to show that these different integrative modalities can benefit patients, just overall. So, again, thinking about anxiety, depression, so prevalent for our patients when they've received a cancer diagnosis or when they're undergoing treatment, and that we have tools like mindfulness-based interventions or yoga that we can utilize to really help support patients.

Again, it doesn't mean that someone doesn't need to have a medication that's added alongside that, but these are other tools that patients can use to really partner with.

I think the other key thing that we often think about with the incorporation of integrative modalities is that it really allows patients to become active participants in their care. You receive a cancer diagnosis; and your world turns upside down. And suddenly, you are having to go in for visits and treatments; and you really lose that sense of control. And so, this is a way of partnering in, helping them become an active participant in what they're doing, and these are interventions that they can really engage in.

**Elissa**: Yeah, that just sounds like a really good plan to be able to even help with side effects, right, and overall quality of life?

**Dr. Huston**: Absolutely. And I think the one thing is that it's not that you have to do all of these things. It's just these are tools that are there and available, so you can draw on them, depending on what your symptom is. It might be something you add in as an adjunct. It shouldn't be overwhelming, but it should be these interventions and resources that are there and available to be recommended again using the evidence that's there, the research that's been done, to partner in alongside for our patients to help with their overall, their wellness, their quality of life as they go forward in their treatment path.

**Elissa**: Okay. So, our final question today, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your professional experience, what would you say to current patients and those who have completed treatment to give them hope after a diagnosis of cancer?

**Dr. Huston:** I think there's tremendous hope, not just with what we know for all cancer subtypes, when I see from early on in my career until now how that landscape has changed in terms of treatments that are available when we talk broadly about all different types of hematologic cancers. But I think there's also hope when we think about ways that patients themselves can partner in. They can add exercise, nutrition, and that we see that by doing those things, they can reduce their risks of recurrence. So, I see tremendous hope with things that we have all around us, these tools that we have available that can be pulled in as part of someone's long-term plan.

**Elissa:** Absolutely. And then when we're looking at, like you were mentioning today, all those Waldenström's patients that have survived for 20 to 29, 30 some years-

**Dr. Huston:** Yes, tremendous hope. Hope was watching the individuals that it's been 20+ years with their Waldenström's and watching them and seeing them thriving and doing well, and seeing that was just such an incredible thing this morning as part of the conference.

**Elissa:** Absolutely, definitely a marker of hope.

**Dr. Huston:** Absolutely, a marker of hope, yeah.

**Elissa:** Well, thank you so much, Dr. Huston, for joining us today and sharing all about your session on integrative oncology. I think it was fascinating, and we'll make sure to include links for more information to the patients who are listening.

**Dr. Huston:** Wonderful. Thank you so much. It's been a pleasure talking with you.

**Elissa:** Thank you.

***Wellness***

**Julie Larson, LCSW:** So, my name is Julie Larson, and I have worked all of my career in oncology-supportive care. And currently I have a private practice where I work with individuals facing any diagnosis of cancer, caregivers, and the bereaved.

**Elissa:** What was the name of your session; and why was this important for you to present on this subject, especially for Waldenström's patients?

**Julie:** The name of my presentation was "Finding Wellness in a Wacky World."

So, the focus on how do we cope day in and day out with the uncertainty, the fear, the worry that bubbles up with this diagnosis, specific for Waldenström's, that idea of having to live with the chronicity of the disease and not always as active of a treatment. A lot of times watching and waiting, which can be hard to tolerate and compromises in immune system. You know, a lot of those things that are unique to this diagnosis.

**Elissa:** Yes, absolutely. Can you tell us some of the highlights of your presentation?

**Julie:** Sure. I like to think that a lot of my presentations, and even my work in my office individually with people, is helping them to sharpen their self-awareness about themselves. So, certainly, we can get quite a lot of comfort and support from others when someone else helps us to reframe things or brings us perspective.

But in this talk, I wanted people to really sit back and think about their own experience with distress and their own awareness of how that shows up for them, and then what they personally find can be helpful to themselves, also, equally important what's not so helpful.

**Elissa:** Yeah, I really liked one thing that you said. You had a diagram on the screen that said, "Thoughts, feelings, and then body" and really for all of us to think about how this stress is showing up. I thought about it, and it seemed to me that it's situational. Sometimes, it will show up in my stomach. Sometimes it will show up in my thoughts first. And, so that was a really good exercise to think about stress and, then name it, right?

**Julie**: Yeah, name it. So, you're right. Our stress shows up in our thinking, in our bodies, and then in our emotions. And then I also said, I find that can be really helpful to think then that you've got three entrance ramps, three different options for the ways then that you can take care of yourself: addressing those wayward thoughts, checking them, challenging them, comforting and self-soothing your emotion and your body or physically getting calm with your body. So, that gives us an option for all of those different things.

**Elissa**: Now one quote that you said during your presentation, which I've actually had this quote on my office for years now, is that, "Cancer has taken so much from you. Don't let it take away your present." What does that mean?

**Julie**: Oh, yes, I'm glad that you had it. I'm glad that it was an anchor for you, hopefully for others too. Because I notice in my office that worry and fear often flashes us forward. It's putting us into a perceived negative future, a scary future, and we get quite consumed, and our attention is flashing into that perceived future.

Similarly, or sometimes we'll really wrestle with feeling guilt or regret, or what if I'd done this? What if I hadn't? What if I'd gone to the doctor earlier? What if I'd done this other treatment? What if I made this other choice? And that's kind of spinning and ruminating on the past where neither the future or the past do we have any control.

And yet if that's stealing all of our attention, it's also stealing us away from our here and our now, our exact right now that we're in and that we're connecting with other people. Where we're living, where we're talking with people, where we're enjoying cooking or enjoying being in a garden or listening to music. That's all happening in your right now.

So, if you're living in your future or if you're ruminating in the past, that's stealing away your present, and so that leads me to that quote of "Cancer has taken so much from you. Don't let it take your present."

**Elissa:** Yes, absolutely. And there was another part that you talked about perspective and balance and that you were more than a cancer diagnosis. So, can you tell us all about that zooming in and zooming out?

**Julie:** Yeah, sure. I love that phrase too, and I can see in my office when something just really hits somebody. And "you are more than your diagnosis," that phrase often hits a lot of people. And they're like, "Yes, I am." Like you feel a sense of kind of protectiveness of all the rest of them. So, I think that's great. I'm glad that you re-mentioned that.

Zooming in and zooming out, kind of this idea of balance, that there are uniquely stressful periods within the experience of having a diagnosis, leading up to a scan or an appointment, being triggered by something that feel heavy and hard and much more uncomfortable. And in those particular times, I find that it can be helpful for people to really zoom in. Break that overwhelming period of time down into very manageable chunks of time, so whether that is day by day or even wake up to lunch. Lunch until doctor's appointment. Doctor's appointment until dinner, and then heading to bed. So, just really breaking that time down, and that can be really helpful and help people feel a lot more in control.

Alternatively, sometimes people can feel just kind of burned out by their diagnosis, by the daily grind of taking care of themselves, of medical appointments, of managing their anxiety and their worry, and that just feels like burnout. And in those moments, how do we sit back and we just get real big, 30,000 foot view, the big picture of you? This is a part of your story. Yes, there's grief in that reality, but you're more than your diagnosis. What are your values? What are the things that have always been important to you? What are the relationships that live alongside you in this big life?

What are the hobbies, the interests, the passions, the fulfillment? What are those other pieces of your big story; and sometimes it's helpful to really zoom out, and get reconnected with that.

**Elissa:** You talked about quite a lot in this one-hour session. For the specific things for Waldenström's patients, you were talking about having it be a chronic disease, watch and wait being stressful, being immunocompromised. Do you have any other specific tips or advice to get around the anxiety and fear and uncertainty that comes with that?

**Julie:** Yeah, I think, my main skill that I would want people to really begin to cultivate for themselves is noticing or getting in the habit of noticing how they're doing each day. Right? Because what's going to be helpful on Tuesday may not work at all on Saturday, or may not work come fall or winter. So, how do you begin to just cultivate this habit of "How am I doing today? Where am I?", and then, now that I've noticed how I'm doing, whether that is, "I'm fine, I'm good, I'm connected, I feel grounded, or I'm struggling today. I'm not quite at my best." Then how do you manage your expectations, get realistic about what makes sense? And I love these two words together too, take compassionate authority or compassionate responsibility for taking care of yourself.

So, sometimes when we're just kind of white-knuckling it through our life or just day to day, day to day, day to day, then we're not really tuning into what am I needing in this particular day? How is this day different than the next day? And when we notice ourselves, then we can take responsibility for taking care of ourselves.

**Elissa:** So, that compassionate authority, is that something like, we talked about giving yourself grace?

**Julie:** Yeah.

**Elissa:** And giving yourself grace when things are not going well, when maybe you're having a really bad day, or when you're not getting back the way you thought you would. Is that what we're talking about with compassionate authority and responsibility?

**Julie:** Yeah, yeah. Compassionate authority it's a blend of two seemingly different words. Compassion, meaning I'm going to be gentle, be kind, be sensitive to myself. But authority that maybe I'm going to need to be flexible with what I choose to do or decide to do in this day.

So, I can't just continue on in the ways that I was functioning yesterday or the ways that I'm expecting of myself. I have to take authority. I have to take responsibility to maybe do this day a bit different than I had planned, than I had wanted to. I have to take some responsibility for that because I can tell that I'm not quite up to 100%. And that's not easy.

**Elissa:** No.

**Julie:** And that's why that authority word is in there because you have to really be honest with yourself.

**Elissa:** Yeah, it seems like a skill that you have to learn as you go, right? So, the longer you do this, the better you might get out of this to be compassionate toward yourself, get better at coping skills, and working through the anxiety.

**Julie:** Yeah, and sometimes people can have a tendency to feel bad about feeling bad, right, or beat themselves up for not being able to do all that they feel like they should be doing. And taking authority means not letting that happen, like protecting yourself.

**Elissa:** Our final question is, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your professional experience, what would you say to current patients and those who may have completed treatment to give them hope after a diagnosis of cancer?

**Julie**: Hmm, hope. I find that the word hope is tricky for some people. Right, you have to grow into those things, in that the experience of learning that hope looks so many different ways. There's so many different ways to find hope, whether it's a big picture hope or whether it's a hope of everybody sitting around the dinner table tonight or, I hope that the weather is beautiful on this particular day. Hope can be so many different things.

I worked with a patient once and she said this, and I love it. I grab things from my patients too. So, I love that you have my quotes on your wall. I have quotes that patients have said to me that I hold and I use too. And I had a patient say to me, "You learn to hold both hope and fear in the same hand."

**Elissa**: Oh!

**Julie**: And I love that because I think that that's true. Right, you're not holding too hard onto either side. You're not steadfast onto hope or you're not just clinging with fear. You're holding hope and fear in the same hand.

**Elissa**: Yeah, I feel like that's very realistic as well, so that you can always have some bit of hope there; but it's okay to be fearful.

**Julie**: I think it's honest.

**Elissa**: Yeah.

**Julie**: It's honest. It's real. How could you not feel the myriad of feelings? Yeah.

**Elissa**: Well, this is wonderful advice, and thank you so much, Julie, for your amazing presentation and then, for talking with us today and talking with Waldenström's patients. We really appreciate you joining us.

**Julie:** Always happy to be here with LLS.

***Neuropathy***

**Shirley D'Sa, MD, FRCP, FRCPath:** My name is Shirley D'Sa, and I'm a hematologist who specializes in Waldenström's and related conditions, and I work at University College Hospital in London, UK (United Kingdom).

**Elissa:** Okay, all the way from London coming to this conference. That's wonderful. Now, what was the name of your session, and why was it important for you to present on this subject, especially for Waldenström's patients?

**Dr. D'Sa:** So, my session had a very apt name. "Neuropathy is a Nagging Nuisance," and indeed that is the case. So, Waldenström's is somewhat different in the way it behaves compared to many other lymphomas, and that's because it is lymphoplasmacytic lymphoma. And what that means is that there are an excess of B cells but also excess of plasma cells, and plasma cells are responsible for producing antibodies. And in most people, that's an IgM; but in a few people, it may be an IgA or an IgG.

Now the thing is, these antibodies, apart from being a good measure of the disease level, so you can use it as a blood marker, they are not inert molecules. They often target cells within the body. And among those are the nervous system.

We think of the nervous system as a series of wires which connect to the brain; and to a large extent, that is fundamentally the case. But actually, each of these wires consists of cells, proteins, lipid molecules, etc. And these can be misread by the immune systems being foreign, and so you can get this autoimmune activity which leads to downstream damage. So people can develop antibodies against something called myelin-associated glycoprotein, or MAG. There are other targets, which are established and can be measured in the lab. There are many other targets that we don't know about because we can't measure them, but they exist.

So, IgM-related nerve damage is not infrequent in WM, and can be a source of great morbidity, lots of symptoms, disability, poor functionality, so this needs special attention in WM. And I think this is what sets WM aside from many other lymphomas.

**Elissa:** Yes. And can you explain for our listeners who may not know what peripheral neuropathy is?

**Dr. D'Sa:** Sure. So, our nerves are a very sophisticated wiring system. Some produce impulses that make our muscles work. Others bring a lot of information from all our cells, our fingers, toes, joints, everything back to the brain so we know where we are in space, we can balance ourselves, we can feel pain and temperature and pressure, etc.

So, when these nervous systems are damaged by whatever cause, and there are many common causes like diabetes and alcohol, etc., but whatever the cause of the damage, what happens is you get neuropathy, a disease of the nerves. So, that is what peripheral neuropathy is.

There are many mechanisms of damage, which can be identified using special tests. Clinical examination's very important but also preferably by a neurologist. But also, nerve conduction testing, also looking for vitamins and things that help the nerves to flourish like vitamin B12.

So, that's basically what peripheral neuropathy is. It's when the peripheral nerve's been affected by a disease, and they are not functioning very well.

**Elissa:** I think most of the time people would think of either pain, numbness, or tingling. But that is not all of neuropathy, right? There could be other symptoms or signs that are having issues.

**Dr. D'Sa:** Absolutely. So, nerves have a vocabulary if you like. They speak pain, they speak tingling, numbness. So, numbness if you like, is an absence. It's a negative symptom. It's something that should be there that isn't. Pain is a positive symptom, and it can be an actual pain like burning. It can sometimes be very vigorous tingling that is reaching an intensity that it's sore and in your face sort of thing. But also, because nerves supply muscles, if they don't work so well, then you can get weakness; and that can affect mobility and functionality.

Then there's this whole other system called the autonomic nervous system, which supplies our organs, it regulates our blood pressure, our pulse, our heart rate, our digestive system. If those are affected by a disease, then you can see malfunction in those systems. And that can be very disabling in their own way and more difficult to pin down. So, yeah, nerves can affect much beyond the sort of more visceral symptoms that people feel.

**Elissa:** You mentioned in your presentation that about 50% of Waldenström's patients are affected by neuropathy. That seems like quite a bit, which is probably why you're talking about this today. What should patients look out for, to where they would want to talk to their doctor?

**Dr. D'Sa:** Because WM is a very sort of inflammatory situation in the body, there's a lot going on. There are a lot of crosstalk within the immune system. People often do develop neuropathy over time, just because of that system. We don't fully understand it, but it's well characterized.

So, when people have neuropathy, I think the important thing is to understand what the tempo is. When did it start? Was there a sudden start or was it gradually built up? What's the distribution in the body? Is it like starting in the toes and coming up the legs? Is it different arms and legs? Is it random areas or is it sort of symmetrical? What is the character of the neuropathy? What are the symptoms? Because if you can vocalize them or write them down, it helps the doctor that you see to begin to form a picture in their mind as to what tests should follow, perhaps.

The sort of way you can help yourself understand things is to set the scene. Write down your story of the nerves and what's been happening over time. What makes things worse. What makes them better? And, and try and get a timeline and how it relates maybe to your underlying WM but also other treatments, other medications you have, and even some things like dietary habits. If someone is really, truly a vegan, but doesn't have supplementation say with B12, simple things can happen; and it's really important not to overlook those things as well.

**Elissa:** Okay. Could you give us some more highlights of your presentation?

**Dr. D'Sa:** So, I think the thing is that nerve symptoms can crop up at any time. They can be there before you're diagnosed. They can develop during the diagnosis, following it, before treatment, etc.

It's important to know that WM can affect any part of the nervous system – the peripheral nerves or the brain, there's a condition called Bing-Neel syndrome, which is when WM cells actually cross what's called the blood-brain barrier and enter in the central nervous system and basically cause problems by taking up space and attaching itself to tissues or in infiltrating tissues.

The take-home messages are that if your nervous system is playing up in a way that seems unusual. Now what I mentioned in that is that oftentimes people, perhaps as they get older, may develop sort of memory problems or something like that. We all worry about memory loss or dementia or something like that. If it's seeming to be quite progressive, if you don't have other risk factors like vascular problems, heart problems, stroke, etc., it's worth checking to see whether the WM is contributing in some way.

So, I think being open-minded, being aware, and asking your doctors to look into things. Sometimes, yes, you may need a scan or a lumbar puncture. I think in the grand scheme, it's worth maybe doing that if symptoms are progressive enough and sort of don't quite fit because if you find something like Bing-Neel syndrome, you can treat it very, very effectively. We've treated dozens of patients. Some have come from places of severe disability and improved and come back to functionality. So, it's really worth knowing about.

The thing is, if you don't think about it, you'll never know. And then, you can reach a point where a lot of damage may have been done. And the same goes with nerve problems. They're very common. There are thousands of causes of nerve damage, but it's good to go through a diagnostic algorithm, if you have WM as well, in case there's a connection because, again, something can be done about it.

Equally, you may have neuropathy and WM, but they may not be related. So, it's important not to get treatment for WM if it is not related because you're having immunosuppressive therapies, you're also using up treatments that you may need later. So, the best way really is to get a consult from, ideally, a specialist neurologist, someone who specializes in peripheral nerve diseases and who has a good connection with your hematologist.

**Elissa:** So, outside of that, you also gave some just general tips that patients can do at home that may be able to help relieve some symptoms. Could you share those?

**Dr. D'Sa:** Sure thing. So, if you have numbness, for example, of your feet or hands, it's very important to be vigilant because what you would otherwise pick up by sensation you may not realize. So, you need to examine your feet and check on a regular basis there's no injuries developing. You need to be sure, if you're stepping into a bath, that you test the water, so you don't burn your feet. If you have balance problems, you should be very cautious the way you move around. You don't want to fall.

It depends what's causing the balance problems. For example, if you have foot drop, then you've lost the ability to correct your posture by the muscles. So, you can seek the help of a physical therapist or someone who can assess you for what are called ankle-foot orthoses, which are kind of contraptions that can be put into your shoe or attached to your leg. And nowadays, actually, the modern technology of these devices has gone ahead in a huge way.  Gone are the days of the old calipers that we used in the days of polio, for example.  There are some really fancy carbon fiber things and light which provide pivoting or a simple device like a foot-up which you can just wrap around your ankle, tie it to your shoelace.  It just helps bring your toes up.

The other thing is if you have tremor, you can sometimes reduce that with beta-blockers like propranolol.  Of course, all medication can have side effects.  I want us to be careful, but sometimes tremor is very, very disabling; and so it's worth doing something about it.

We've also even sometimes given Botox® injections into-

**Elissa:**  Oh!

**Dr. D'Sa:**  -hands and muscles because tremor relies on one muscle going one way and the other muscle going the other way.  If you block one muscle, it can reduce tremor.  So, periodically you can have that done.

The other thing is just sensible keeping fit, active, exercising.  If you have impairments because of neuropathy, it doesn't mean that you've got no function.

**Elissa:**  Right.

**Dr. D'Sa:**  Whatever function you have, you can make that work better, and that can help you cope better with your neuropathy.

Ideally, best to do it under the guidance, at least as a one-off, by a specialist in physiotherapy (physical therapy) and a  neurorehab because they can give you pointers.  They can give you safety tips.  Then you can do that stuff yourself.

It's important to know that when you do these things, you're not going to see a change in a day or a week.  It takes weeks, so it's best to sort of think about it in chunks of a few months and maybe keep a diary.  Say look, "Now I'm feeling like this," and then a few months later if you say, "Oh, actually, I can do this now, so I have made progress," it can give you hope. You can show yourself that what you are doing is making a difference because, quite often, when you get a diagnosis like WM or other diseases, you feel completely powerless. And I think this way you can feel you're actually doing something yourself.

And, frankly, exercise just boosts your mood as well; preferably outdoors if you can. Out in nature, just because connecting with nature, I think, is hugely therapeutic as well.

**Elissa**: Absolutely. Yeah, I think exercise and balance training, stretching is all very, very good advice for patients.

Our final question today, speaking of hope, we have a quote on our patient podcast home page that says, "After diagnosis comes hope." Based on your professional experience, what would you say to current patients and those who have, may completed treatment to give them hope after a diagnosis of cancer?

**Dr. D'Sa**: So, I specialize in WM. And what I would say is when I first meet a patient with WM, we are embarking on a long journey together because people with WM typically live with their disease for a very long time.

Secondly, what I say to people is there are different clocks in the WM journey. Most of the time the first clock, which is when the disease first starts, is unknown to anybody. There then comes a time when the diagnosis is picked up. Now, that may be by chance because someone sent a blood test; and you have a spike in your IgM or something and they go, "Oh, what's going on?" They do a bone marrow, etc. And you may be feeling perfectly fine, and you go onto a program of active monitoring.

But that is the second clock, when you're picked up as having the diagnosis. Now that part of your journey can last for many years, actually. Some people it lasts forever. They never need treatment.

So, the third clock is when you have to start treatment. So, I think because the time from clock one to clock two and three can be already many years, when you first get a diagnosis, it's important to remember that you've probably had this already for several years. So, actually, what's changed is you now know about it, but it's been sitting there anyway.

The third clock, which is the treatment clock, I think it's the start of a new phase in your journey. Okay, there comes a time where you may need treatment, but the treatments we have for WM are very effective. By and large, people get excellent responses to what we can treat them with.

There's this thing called a bell-shaped curve in medicine where, it literally looks like a bell, like a hill, if you like. Most people are sitting in the middle of that peak. Most people have certain experience of treatment response. There's a few in the tail on the left side who may not respond so well to treatment, and there are a few on the other tail who do amazingly well with treatment.

So, most people are not in the bad tail or the really good tail, so people generally do well. They're in that big humpy bit. And because even chemoimmunotherapy is so effective in WM, that's still my first go-to for WM because we know how chemoimmunotherapy works. We've a lot of experience of it. We can use it in a nuanced way so that we get the benefits without causing too many problems.

In the knowledge that we also have access to some amazing new therapies that are coming online. Many treatments, particularly in the US, such as BTK inhibitors, are available from the get-go. Many countries cannot do that. But, you know, I do think that sometimes using traditional therapies that have a long track record has a lot to say for it because newer therapies are fantastic, but some of them are long-term continuous therapies. And although that's popping a pill or two a day, one has to do things in a nice sequence, which is very tailored to the patient. Over time, some of the newer therapies can develop side effects, etc.

Now the other good news is that we've learned so much about how to manage those side effects.  So, you can adjust the dose, if you have heart rhythm problems, you can speak to a cardio-oncologist.

So, what I would say, the hope side of WM is that there are so many new therapies already available, which is fantastic; and there are tons more in the pipeline, because there's a huge community at work in researching this disease.  It's a very closeknit community, and we are determined to have people at WM live forever, if we can, basically.

So, I think there's so much to be hopeful for.  And whenever I see a patient for the first time, I really, really emphasize that because my experience is that people remain in my clinic for years to come.

**Elissa:**  Yes.

**Dr. D'Sa:**  We develop almost like a friendship.  I get to know them, and for me as a doctor, that is a privilege, actually.  I really, really enjoy that aspect as well.

**Elissa:**  Yeah, I think we're seeing that also at this conference when we're seeing people that are 20 to 29 years out; and it's incredible.  And so, I think that gives so much hope to certainly newly diagnosed patients or maybe patients who've only been diagnosed a few years ago.

So, thank you so much, Dr. D'Sa, for talking to us today and telling us all about peripheral neuropathy and what patients can do if they are experiencing that.  So, we really appreciate your time.

**Dr. D'Sa:**  My great pleasure.  Thank you.

**Elissa:**  Thank you.

This concludes our episode podcasting live from the 2024 IWMF educational forum. 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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