



CLL SOCIETY

Webinar Transcript

Navigating Integrative Medicine Approaches in CLL

March 19, 2024

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This text is based on a computer-generated transcript and has been compiled and edited. However, it will not accurately capture everything that was said on the webinar. The time stamp is approximately 10-minutes off due to editing. The complete recording of this webinar is available on-demand.

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Hello and welcome to today's webinar. I am Robyn Brumble, a registered nurse and CLL Society's Director of Scientific Affairs and Research.

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At CLL Society, we are dedicated to providing credible and up-to-date information to the CLL and SLL...

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community because we believe smart patients get smart care. As a reminder, you can rewatch all our educational programs by going to the section of our website called Education on Demand.

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This program was made possible through support from both our donors and our industry partners. At this time, I would like to introduce our moderator.

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Thank you. Thank you, Robyn. I would like to welcome our audience to today's event.

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We are joined by my colleague, Dr. Onyema Okolo-Taku. She's a medical oncologist at the Ironwood Cancer and Research Center in Gilbert, Chandler, Arizona, and is part of the CLL Society's Medical Advisory Board.

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We also have patient advocate Stephen Brown will be joining us to share his CLL journey and the 4 pillars that have helped him live well.

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We'll have questions that will form the large part of the meeting and that will be answered by Dr. Okolo-Taku...

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and also by Stephen at the end of the session. So please take advantage of this. And ask your questions in the Q&A box.



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Before our speakers join us, we have a brief message from CLL Society's Development Director, Ron Katz.

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About our fundraising towards research in integrative medicine and CLL. It's my pleasure to welcome Ron Katz.

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Hello, I'm Ron Katz, Development Director for CLL Society. Thank you for joining us today.

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We know that many individuals report receiving tremendous benefits from integrative medicine practices and you will hear about some of these from our speakers today.

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But real scientific data to support the clinical benefits of integrative medicine for CLL and SLL is limited...

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and funding to conduct research in this field remains significantly lacking from other sources. CLL Society's new research grant...

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will supply much needed funding to scientists who are committed to this area of study. And we need your support to make it possible.

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In 2023, CLL Society was very fortunate to have received matching gift commitments from two very generous donors, ...

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the Sim Einstein Research Foundation and Vigyan Singhal. Their support and encouragement helped launch our effort to introduce an integrative medicine research award this year.

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Every dollar that you donate towards our integrative medicine research campaign will be matched by these generous individuals.

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As of today, we need just over \$20,000 to complete this matching opportunity and fully fund the succeeding research effort.

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As you listen to today's program. Think about how useful this scientific research can be and please help us reach our goal.

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Just go to the link shown on the screen to make your donation. This link will also be sent to you by email in the post-event email survey.

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You can also go to our website, cllsociety.org and click on the header for the integrative medicine campaign.

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If you have questions, you can always feel free to send me an email at rkatz@cllsociety.org.

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On behalf of the entire CLL Society, I thank you again for your support. And now I would like to welcome our next speaker...

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CLL Patient Advocate, Stephen Brown. Hello everyone. Thanks for having me, my name is Steve.

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And I'd like to give you a brief snapshot of who I am, kind of by the numbers.

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I am a 64 year old guy. I've been married for 38 years as of this year.

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For the last 5 of those years, I've also been the primary caregiver for my wife...

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who suffered an aneurysm during a stroke, I'm sorry, in surgery, nine years ago.

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I have two kids, four grandchildren, one dog, three grand-dogs...

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three grand-cats. I have been an athlete my entire life and an endurance sports junkie since the mid-1980's.

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And to date, I have completed 27 marathons, 13 Ironman triathlons. A couple of 100 other events of varying distances, including a very cool ultramarathon in South Africa with my good friend Ethan Zhan, if any of you out there are fan of the show survivor.

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Chat more about that later with anyone. For 18 years I've been living with CLL, which has led me down a path of 54 doses of chemotherapy.

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But most importantly for the last three years, I've been on a targeted oral therapy medication that has done a great job at keeping my symptoms quiet.

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Hey, without any side effects. So that's kind of me in a nutshell or in my elevator pitch, if you will.

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And having been an athlete my entire life and in pretty darn good shape when I was first diagnosed, that diagnosis came out of left field and it was a real shock for me.

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And because my lymph nodes were out of control and my blood work was quite askew, I needed to start treatment right away which is which is what we did.

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But I consider myself one of the lucky ones in that I responded then and I continued to respond very well...

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to any treatments that I've undergone through the years. And I kid you not, and I swear behind this and I'll scream it from the highest mountain...

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that my disease has opened more doors for me than it has closed and it's created more opportunities that it's taken away.

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And I know that sounds crazy. But it's the truth and among the many opportunities that I've had a chance.

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It is the opportunity to be a patient mentor for so many newly diagnosed patients and their families,

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on making those connections. It's meaningful for me because it seems to give my disease a real sense of purpose.

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It's solved the why question. And it's also meaningful for the patients and their families that engage because they get to make a connection with a success story in me, which can give them hope and help clear some of the fog and of the unknown that usually comes with a diagnosis.

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So one of the things that has kept me sane through all of this in life is these four guideposts that I created for myself, which I'm going to share with you now.

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And it's the monitoring of these guideposts that have helped keep me emotionally balanced and healthy.

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And as a result, physically balanced and healthy. And this can be applied to just about anything in life and not just for disease, not just for cancer, they're not just for CLL, they are kind of like life.



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Checkpoints where I can evaluate to make sure that the tanks are all topped off and leveled off and I'm in a good...

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emotional mental space. And those keys are feet, choice, chocolate, and movement.

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I guess you want to know a little more, right? So feet. Simply put - am I remaining where my feet are at all times?

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Am I present, am I grounded? Am I not worrying too much about what's ahead of me?

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What's behind me, what's left, what's right? I just need to stay focused, stay present, and be where my feet are at all times.

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Choice. A lot of times we get hung up over the fact that we need to make a choice.

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We don't know what it should be. We panic over the various choices. Or we neglect the fact that we have so many choices and we can't make a decision or we can't make a choice.

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So, I think focusing on the choices that need to be made and understanding what your options are is key to minimizing some anxiety in life in general, and especially with disease management.

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Chocolate is my metaphor for, and I'm not talking about a Hershey product here, but my metaphor for essentially feeding your emotional sweet tooth.

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Do the things that you need to do, that make you feel whole, that make you feel. Have that feed your soul and feed your spirit. And I think movement, and it goes...

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without an explanation, right? We all know movement is medicine. We all know the importance of staying in motion. I for one, believe that CLL can't and cancer in general...

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has a harder time hitting a moving target. So, I think that's always been my model in life,

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and even more so recently since my diagnosis.

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I think my time might be nearing an end but before I go I just want to remind folks of a couple of the resources that are available through the CLL Society.



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There are over 40 groups that meet virtually and are open to people with CLL and their care partners. In addition to the geographically based support groups, there's also...

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Watch and wait support groups and a veterans with CLL support group. CLL also has a board certified chaplain...

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available for one on one meetings, and these are for people from all faiths or no faith,

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that can help as a support for those with CLL and for their families as well. And she can help with coping mechanisms.

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She can help with spiritual reflection, grief support, and a lot more. So I encourage you to please check them out.

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So valuable resources there. And at this juncture, I would like to thank you again for having me and welcome our next speaker, Dr...

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Okolo-Taku.

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Hi everybody, my name is Onyemaechi Okolo-Taku. I am a medical oncologist and hematologist.

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I work in the Phoenix area and I'm happy to be here with you guys today to talk about some of the integrated medicine approaches in CLL.

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At the end of the presentation, we'll have some time for questions as well. So I hope you enjoy the presentation.

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Let's get started.

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So here I am. I'm Dr. Okolo-Taku. I did my internal medicine residency as well as my hematology and oncology fellowship and my integrated medicine fellowship at the University of Arizona in Tucson.

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Go Wildcats! And that's really where my interest in integrative medicine really took hold. So I wanted to become a hematologist when I was a young child, although at that point I didn't actually know what it was.



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I was born in Nigeria. I lived there till I was eight before moving to the US and eventually to the UK.

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But as somebody from West Africa, I was always aware of a specific condition called sickle cell which is a type of inherited anemia, low blood counts, which is very prevalent in West Africa.

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And I remember as a young child thinking, how do we treat something like this? Because I had, you know, a second cousin that had this illness that was just always ill.

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So that was kind of the first time that I began thinking about wanting to be a doctor. It was later on, in medical school when we were doing our histology lectures and pathology lectures, that you know learning about cancer really started taking root in me and then when I realized that there was actually a joint fellowship with blood disorders and cancer.

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For me, that was it. And when I started my clinical side, which is when we start seeing patients, no longer just the textbook...

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I realized that there was almost a missing component of what we were learning and that was the human component. That was the patient component,

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The patient doesn't really have that much power as far as dictating how their care goes. Our treatments are so complex and so complicated and almost always need to be given...

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either in a hospital or in the clinic but more so recently we have the utility of oral medications, thank goodness.

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But when I was in training, I remember patients always asking me, What can I do to help? I know that you know what you're doing.

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I know that you know what chemo to order for me and things like that, but what can I do for myself?

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And additionally, being from a multicultural background, I always knew that there was, you know, more than one way to address specific illnesses.

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You know, in West Africa there's certain methods that people utilize here in the US, you know, there are different cultures, Native American cultures of medicine.

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And so, when I realized that there was another fellowship that I could take in addition to hematology and oncology that would really in my opinion, solidify the way I wanted to treat patients,

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I signed up right away and that's what led me to integrative medicine. Now, like all medicine specialties, it's very, very broad.

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There are so many complementary types of medicine that are part of integrative medicine and I specifically am interested in nutrition.

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For me, I have a family. I have two young children. It's very important to me to, from a young age, to bring them up in a way where we understand how important nutrition is, not just, you know, our physique, but in the long term.

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What does what I eat affect? How my life is going to look in 2030 years when it comes to illness.

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And so that is why nutrition is particularly important to me.

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So here's our table of contents and what we're going to be discussing as most of you will already know the definition of CLL and SLL, but we'll go over it briefly.

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We'll talk specifically about what integrative medicine is and within that what integrative oncology is. We'll talk about why you might want to consider integrative medicine as part of your CLL journey.

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And then, we will dive deeper into the data on certain integrative medicine approaches in hematologic cancers such as CLL and again focusing mostly on the nutrition and also on some cancer related fatigue which is a big symptom point in people.

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CLL or chronic lymphocytic leukemia is a cancer affecting the white blood cells, specifically mature B cells.

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This is different from immature cells which tend to be more of the acute leukemias. It is a non-Hodgkin lymphoma.

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And the cells typically have what we call a CD 5 positive marker. That's more important for the physician and the pathologist when it comes to diagnosing the condition.



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That's one of the things we look out for more specifically. So essentially these cancer cells, it's one abnormal cell that continues to clone itself over and over and over again, eventually disrupting the way your bone marrow functions and how your whole body functions.

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So ones of these abnormal CD 5 positive B cells accumulate in the body in the bone marrow, in lymph nodes.

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Sometimes in the liver and the spleen and disrupt normal functions. Another entity basically the same as CLL is SLL which is small lymphocytic leukemia and it has the identical marker...

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CD 5 positive cells. But it's characterized by being present specifically just in lymph nodes and the amount that is picked up in the blood is much less than we need for the threshold for diagnosis of CLL.

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So signs and symptoms for many people with CLL is discovered incidentally. I will say for at least 60 to 75% of the patients I see in clinic.

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The referral I get is from her primary care provider who was doing an annual physical on a patient and also took some blood.

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And it's within that blood work that we see some abnormalities in the lymphocytes within the white blood cell and that's when I get the patient referred to me for further workup to say, hey, is this real?

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Is this something concerning? What are the next steps? Sometimes though people are diagnosed because of enlarged lymph nodes that are often painless.

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These can be lymph nodes in the neck area, in the axilla, which is under...

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the arm sometimes in the inner...

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region, which is around the patient present with lymph node, you know, in the head area behind the head, so things like that.

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And then a small percentage of people are diagnosed after they are seeking evaluation because they're having these chronic...

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non-specific symptoms. So these are things like, low grade fever without a source of infection ongoing for greater than 2 weeks,

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just intense fatigue, unintentional weight loss, drenching night sweats.

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And then we have the very, very small population of people who come in with what we call immunodeficiency disorders.

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So the CLL is essentially a disruption of your immune system as well. And so people will come in with disorders because of that.

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Something like hemolytic anemia. So that is an anemia which is when your red blood cells are low.

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But hemolysis is when your body is destroying these red blood cells on its own. Something like pure red cell aplasia is whether your bone marrow stops creating red cells specifically, but the white blood cells are still raging and increasing in number.

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And then something like thrombocytopenia, that's when your blood platelets are low and the side effect of this is increased bleeding risk, increased bruising risk.

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So sometimes people will come in because of that. But regardless of how one comes in to see the oncologist,

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the workup is pretty much the same, which usually includes drawing blood, evaluating with something called a flow cytometry to look for that marker that we discussed sometimes lymph node biopsy if the presentation is just with lymph nodes.

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And then once in a while we might also do a bone marrow biopsy.

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So the big question. CLL can be a very indolent disease. This means slowly progressing more of a simmering type of leukemia.

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But there are certain symptoms that can be so disruptive to people's quality of life that even if one is not ready for CLL specific treatment, you may want to treat some of the symptoms that you're having because of it.

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Fatigue, as I mentioned before, is one of the biggest complaints I hear from patients. And cancer related fatigue as a whole.



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As one of the most frequently cited complaints by people with cancer in general. So both solid tumor and blood cancers.

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And as I mentioned before, many people are always asking, what more can I be doing?

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So, integrative medicine. This is a growing field of medicine. It's combining the most well researched conventional medicine with the most well researched and evidence-based complementary therapies to achieve the most appropriate care for each patient.

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So it's a very individualized approach to taking care of patients using what we learned in med school with a lot of the techniques that are happen present and utilized globally for centuries as well.

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It is a whole person-centered understanding that health care involves not just physical but mental, emotional, and spiritual care as well.

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And then going deeper still into integrative oncology. The Society for Integrative Oncology, which works closely with other oncology groups like ASCO, the American Society of Clinical Oncology, and the American Society of Hematology,

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have made an official definition for integrative oncology. It is a patient centered evidence-informed field of cancer care that utilizes mind and body practices, natural products, and or lifestyle modifications from different traditions alongside conventional cancer treatment.

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Integrative oncology aims to optimize health, optimize life and clinical outcomes across the cancer care continuum.

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And to empower people to prevent cancer and become active participants before during and beyond cancer treatment.

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So why should you consider integrative oncology? Mostly because you're probably already thinking about what you can be doing by yourself at home, but you don't have a word for it.

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You did not know that you were looking into integrative oncology techniques to help alleviate some of the symptoms that you might be having.

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So according to the World Cancer Research Fund and the American Institute for Cancer Research, the most common unmet needs among people with cancer are psychological.



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This means anxiety, depression, fear of cancer. Recurrence if you've already gone through the process as well as cognitive problems.

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As a result of this, it's estimated that up to 47% of people with cancer are already using some sort of complementary alternative or integrative therapy during their cancer treatment.

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There is one report that estimates as high as 89% of people with non-Hodgkins lymphoma, which includes CLL, are using complementary and integrative medicine.

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Unfortunately, the problem with this statistic is that most people are undertaking this journey by themselves.

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They are not sharing with their oncologists that they are utilizing these practices and a lot of it is because of fear,

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of judgment. Fear that the oncologist will shut it down, fear that the young oncologist just doesn't know much about what they're doing and so as a result just doesn't want to approach the subject.

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And the risk associated with this is that without the patient sharing this with their treating physician, their oncologist,

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we are unable to make sure that you are doing what you are doing in a safe manner. Without a complete knowledge of the supplements one is using with the medication,

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you're using. There can be dangerous drug interactions that we are unaware of. So, you as a patient may inadvertently be putting yourself at risk.

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By utilizing practices with limited or no evidence that could also reduce the efficacy of your cancer treatment.

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So for me, I always tell patients. I'm not here to judge you. I'm here to help you.

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I'm here to partner with you. So let me know any and everything that you are putting into your body so that whatever I give you, we're able to make sure that no harm comes your way.

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So the integrative oncology, it's a partnership, it's a partnership between the patient and the physician and it's used evidence...

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to help you use complementary practices in your cancer. So it helps fill the gaps in the unmet needs that we talked about earlier.

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So examples of integrated medicine approaches are things like nutrition, exercise, botanicals and supplements.

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Movement medicine - So these are things like, yoga and Reiki, meditation and mindfulness.

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Energy medicine as well as medicine from other cultures like traditional Chinese medicine, traditional Korean medicine, Ayurveda, etc.

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So let's get into the nutrition aspect. So questions I often get asked are, is there something I can eat to fight this?

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Do I need to cut out sugar? You know, everyone is talking about sugar is the big bad wolf, you know.

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Was this caused by a bad diet? Do I need to eat organic foods only? So research I have found that dietary factors are among the leading cause of death in 195 countries including the United States.

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And in fact, diet or dietary factors is a greater disease burden than smoking. Nutrition can reduce survival in many cancers and can also make it hard for a person to tolerate cancer directed therapies.

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I typically will start by evaluating my patients. CONUT (Controlling Nutritional Status) score. This is a score that helps assess one's overall nutritional status.

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It looks at a person's albumin, their cholesterol, and their lymphocyte count.

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And it has been shown to be an independent prognosticating tool. Particularly for patients with B cell...

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leukemias and T-cell leukemias lymphomas. Essentially a score less than four which basically is normal to only mildly impaired...

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is associated with better progression-free survival. I know better overall survival in patients with aggressive lymphoma's like diffuse large B cell, leukemia, and it's sort of aselling bonus.

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So although not specifically looked at for CLL, I like to use it as just a baseline to see where my patient's nutritional status is.

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Supplements. So the use of high dose supplements is very tricky, especially in cancer care.

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Because unlike prescription medications, supplements do not have to go through the same kind of rigorous checks with the FDA.

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Supplements, you can walk into any store, a Sprouts, a Whole Foods, pick up any number of supplements and just start taking it.

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There are no checks and balances as far as a pharmacist looking over things, doing interaction checks and things like that.

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And that's kind of what makes it dangerous. And also because it doesn't have to go through the FDA.

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There aren't really a lot of clinical trials utilizing specific supplements when it comes to treating or managing...

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many conditions, including cancer. And so the official stance for supplement use in integrative medicine and integrative oncology...

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is that high dose supplements have not consistently demonstrated protective effects of micronutrient with regard to cancer.

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So the recommendation is that instead of supplementing primarily, you get your nutrients from a balanced and healthy diet...

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and that is what looks to be protective against cancer. Of course, there are some supplements that have higher interest and so more and more research is being done.

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And in the world of CLL, those include things like green tea and curcumin or so there was a study, phase 2 clinical trial done at the MAYO, evaluating how much green tea extract might be protective or helpful...



CLL SOCIETY

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in patients with a CLL. The study was done for 6 months in 42 patients and it used a dose of 2,000 milligrams.

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One a day. Now for context, one cup of green tea contains variable amounts of EGCG but a high estimate of 78 milligrams per 100 milliliters means, that people were drinking up to 22, 8 ounce cups of tea a day.

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Now I don't know about you but I couldn't drink that much.

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I couldn't drink that much green tea but in this clinical trial that's the dosing that they were using.

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The most common side effects were nausea, diarrhea, liver inflammation.

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The liver inflammation was mostly mild. 12 patients did discontinue. One patient had partial remission.

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And 30% of the patients had a decline in their absolute lymphocyte count of greater than 20% lasting for over 2 months.

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And about 70% of those with enlarged lymph nodes experienced a 50% reduction in the size of those nodes.

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So green tea based on this study is generally considered safe. But keeping in mind there is the side effect of liver inflammation.

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So what I tell people is go ahead drink green tea. I wouldn't drink large, large volumes of it.

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But if there is underlying liver dysfunction, if a person has cirrhosis or hepatitis or anything else like that...

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I wouldn't chance it. There are other things that we can we can look into when it comes to supplement use for CLL.

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Turmeric, is, a, a spice that is utilized in many parts of the world in cooking things like curries, making things like golden milk, which is a type of tea.



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And so it's also highly utilized in our ayurvedic medicine, which is a primary type of medicine culture used in India.

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And so a lot of people are interested in this because it has some cancer fighting properties in it as well.

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And in a clinical trial utilizing CLL patients, 21 with high absolute lymphocyte counts, who were at a stage 0 to one.,,

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Some people did have nausea and diarrhea. There were no objective responses but four patients did have greater than 20% reduction in their absolute lymphocyte count.

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But once they stopped using the turmeric, it did start rising again. One important thing about turmeric, it needs black pepper...

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to be able to be active within our bodies. So for somebody who regularly takes turmeric or drinks it in tea make sure you're adding some black pepper to it so that it actually becomes activated.

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But all in all between the green tea and the turmeric, they are likely safe, with some activity, but the efficacy is unproven and may be minimal.

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Sugar. So we found that high fasting insulin levels are associated with an increased risk of recurrence and death in breast cancer specifically, but the data is unclear in hematologic malignancies, blood cancers.

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Sugar present in foods naturally doesn't look to be problematic, but there is increasing data that consumption of added sugars, so sugary beverages, high fructose corn syrup, artificial sweeteners like aspartame as well as foods with high dietary glycemic loads can affect treatment response and also increase the risk of relapse in certain types of cancers.

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So as I mentioned, aspartame, which is an artificial sweetener, may actually increase the risk of hematologic cancers like CLL.

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This is especially important to me because a lot of patients will come in and say, I've cut out sugar, I'm no longer taking sugar, but they don't mention that the replacement of sugar they're using is artificial sweeteners and so again disclosure is so important when it comes to partnering with your



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physician because although you think you might be doing one thing that's good for your health by cutting out sugar, by adding artificial...

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sweeteners you might actually be worsening your risk.

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Organic foods. This is a big topic because organic foods might be in my opinion the more important tool a person can have...

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in controlling their risk of something like CLL and also potentially keeping the disease up in the indolent phase for as long as possible.

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And I'll get into why I think that, shortly. But organic foods, these are foods that are processed without synthetic chemicals or fertilizers, pesticides, genetic engineering, or radiation.

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There's research that's shown that several pesticides are carcinogenic. In fact, research on occupational pesticide exposure has shown that there is an association with pesticide residue and an increased risk of non-Hodgkin's lymphoma.

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So people like farmers, we are seeing higher rates of things like CLL.

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So people like farmers, we are seeing higher rates of things like CLL in that population. High organic food intake on the other hand has been shown to be associated with the decreased risk of developing...

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non-Hodgkins lymphoma. So specifically, veggies and citrus fruits consumption may actually help in survival.

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And certain fruits and vegetables contain potentially protective substances. So these are things like beans, berries, flax seed, garlic.

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You know, we talked about green tea and then things like tomatoes as well. So, price point.

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Organic food in this country is not cheap, it's very expensive and so decisions have to be made especially for individuals with limited resources.

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Although organic food is preferred, it is something that you don't have to go full organic on certain fruits and vegetables.



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The Environmental Working Group releases a list every year about foods that are clean versus foods that are not clean.

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By not clean, we mean foods that are typically always found to have residues of pesticides in it.

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So the clean 15 are non-organic foods that you don't necessarily need to purchase organic because the amount of pesticides on it is negligible.

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Whereas the dirty dozen are fruits and veggies that more often than not, need to or if one is able, should be purchased organic.

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So this is the list from 2023 the dirty dozen. So high pesticide residues, strawberries, spinach, kale and collards, peaches, pears, nectarines, apples, grapes, bell and hot peppers...

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cherries, blueberries, and green beans. So whenever possible, prioritize buying these fruits and vegetables organically.

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And then the Clean 15 list, these are ones that you can, you don't have to worry about organic, typically avocado, sweet corn, pineapples, onions, papayas, frozen sweet peas, asparagus, honey dew melon, kiwi, cabbage, mushroom, mangoes, sweet potatoes...

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watermelon and carrots.

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As I mentioned before, certain fruits and veggies, beans, berries, garlic, cruciferous, vegetables like broccoli, brussel sprouts, broccolini...

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flax seed, green tea and tomatoes may be beneficial in preventing cancer recurrence or as consumption of foods from animals such as red meat, milk and dairy may lead to relatively increased risk of developing hematologic malignancies.

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We've seen these already correlated in solid tumor cancers like colon cancer where high consumption of red meat and animal products actually increases...

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one's risk of developing colon cancer and we're starting to see the same thing in hematologic malignancies as well.

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So what diet does the Society of Integrative Oncology recommend for people? It's the Mediterranean style diet.

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Doesn't mean that you have to be a vegetarian or anything like that. It's actually very accessible and and delicious, in my opinion,

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way to consume your foods. It's mostly plant-based, minimally processed, lots of fruits and veggies, whole grains, nuts and legumes.

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Your primary cooking fat is going to be olive oil. And although you can consume things like cheese and yogurt, it should be in low to moderate amounts. You want to consume fish and poultry. You want to limit red meat -

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I'm consuming it more infrequently and in smaller amounts. And for dessert, you want to prioritize fresh fruits limiting sweets containing added sugars and then if you drink wine, consume it in low to moderate amounts.

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So the patients who had a higher MEDLIFE score, and the MEDLIFE is the Mediterranean lifestyle index.

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It is based on the Mediterranean diet. It is a 28 item survey containing questions about food consumption,

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dietary habits, physical activity, rest and social interaction. And everyone, once you take it, you were scored, items are either assigned a score of 0 or 1 point with a final score ranging from 0 to 28.

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And so individuals with higher MEDLIFE scores were found to have 29% lower risk of all- cause mortality and a 28% lower risk of cancer mortality compared with those who have low scores.

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So the more you adhere to a Mediterranean diet, the higher your chance of survival in the face of cancer is what we're finding out more and more.

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So cancer-related fatigue, this is, like I mentioned earlier in the presentation, one of the highest complaint points that I hear from people with CLL.

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Sometimes it's the only physical symptom that a person can have for a very, very long time.

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CLL SOCIETY

It's not usually alleviated by resting and it is thought to be related to an immunologic process that comes with CLL.

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So the SIO, the Society of Integrated Oncology, recommends proper diet, hydration, and physical activity to help alleviate cancer related fatigue.

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So this can be, you know, counterintuitive. You feel tired, but the recommendation and what we're finding is that people who actually increase their physical activity experience less cancer-related fatigue.

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A meta-analysis, a study of a 113 studies, showed that pharmacologic treatments do not actually improve cancer related fatigue significantly but exercise and psychological interventions have had more positive effects.

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Additional tools that can help with cancer related fatigue: acupuncture and acupressure.

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These are very, very big tools in the world of integrative oncology. A 2,020 meta-analysis showed that acupuncture treatments when properly performed, meaning done by a trained professional, can reduce cancer related fatigue by a significant factor.

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We also use acupuncture and acupressure in patients who are experiencing chemotherapy related peripheral neuropathy as well.

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So additional tools that can help with cancer related fatigue - touch therapies. So things like massage, Shiatsu, reflexology, and nutrition in the nutritional supplements that we discussed earlier.

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Mind body techniques, so these are things like mindfulness and hypnosis. Things like yoga, movement, like Tai Chi and Qigong.

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And then circadian rhythm management, something interesting about CLL is that one study showed that a person's melatonin levels, so melatonin is something in our body that helps us sleep, it increases in the nighttime and decreases in the daytime.

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And levels were considerably lower in patients with CLL than in healthy individuals showing that people with CLL...

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were not getting good sleep and this may be related to the disease itself. Therefore, good sleep habits are so important when one's melatonin levels are already lower.



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And then the use of melatonin supplementation can also be considered as well. So if you are getting enough rest and exercising enough...

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and optimising your nutrition, this might help reduce your overall fatigue related to this cancer.

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Exposure to morning bright light can also reduce chemotherapy related fatigue. So in the morning, get up, raise your blinds, try to spend a few minutes out in the sunlight.

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Studies have shown this to be very, very useful. Things like omega 3 fatty acids, so that's EPA and DHA...

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these are found in fish, fish oils, as well as flax seed and soy and walnut oil.

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They can not only decrease the risk of total mortality and mortality from cancer, but studies have shown that it can also decrease cancer related fatigue.

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Finally, something like American ginseng can also improve symptoms related to cancer fatigue.

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There's so much more though. When it comes to the world of innovative medicine and integrative oncology, we've only just scratched the surface today.

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So if this is something that you are interested in, there are resources all over that you can utilize.

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I trained at the University of Arizona at the Andrew Wiles Center for Integrative Medicine. And I've provided a link here.

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I'm at the bottom of the slide. That you can jot down. If you are interested in consulting with an integrative medicine doctor, there is a list on that website of different alumni, all over the country, all over the world, many people who also do telemedicine consultations.

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If you have more questions or just want to have a medicine consultation or have a one-time consultation with them to kind of go over what's going on in your health and how you might be able to integrate integrative medicine practices into your armada of...

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treatment. Thank you so much for your attention today. Here are some of my references and I will be available to answer your questions.



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Oh wow, that was. Just amazing. I thank you.

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So much. I hope everyone enjoyed those presentations as much as I did.

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And I can't wait to get to the questions to Steve and Dr. Okolo-Taku, there's just a million questions that have come in.

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We're going to try to get to as many questions as we can. But if we're not able to get to your questions, please feel free to mail them to ask the experts.

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And we'll share that email address on the closing slide. These slides will also be available later. All of that will be available to you.

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Let me start, Dr. Okolo-Taku, let me ask you this, just some basic logistic things.

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There is a comprehensive list of graduates from the Andrew Weil Center for Integrative Medicine who wanted to be listed as potential...

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target points for patients people who are interested. Although the university is in Tucson, Arizona, we have graduates who are all over the country, all over the world and you can actually filter your search based on your location as well.

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Although not as easy, you can also go through your insurance to try to find integrative medicine practitioners in your area. More and more insurance is understanding that this is a big interest for their patients and so are making those lists available as well.

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So outside of the Andrew Weil Center for Integrative Medicine, there are other fellowship programs also in Stanford.

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They also have integrative medicine program and so their practitioners are again all over the country so it's just a little bit of footwork by the interested person but you would definitely be able to find somebody in your area.

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Oh, key point. Telemedicine. So in some regards, sometimes location doesn't even matter.

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A lot of people do offer consultations via telemedicine.



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And let me ask you this because you touched on insurance coverage. Because I've looked into integrative oncology and a lot of the lab tests which are often functional medicine tests don't seem to be covered by insurance which can be very expensive.

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What's your experience with patients having coverage? For seeing the doctor, getting the tests, and some of the therapies that you mentioned, what's your experience with insurance covering that?

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What do you?

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So I don't have a lot of personal experience when it comes to the insurance just for integrative medicine consultations.

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I practice mostly in the capacity as a medical oncologist and the way I practice is that in addition to my conventional cancer treatments, I always ensure that my visit times with the patient include a few minutes of discussing some of the integrative medicine and lifestyle changes a patient should make.

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So I personally bill as an oncologist, but in my practice we do have a physician who she does just integrative medicine consultations for us and she bills differently and I think she mostly bills under the internal medicine kind of primary care type of billing model, but there are so many different models available for people and there's also private pay because sometimes like you mentioned, insurance simply just doesn't play ball in some of these

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so it's going to be asking the person that you end up talking to upfront. What's your billing technique?

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How do you expect me to pay for this? Do you take insurance? And there are a lot of practitioners that do.

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No, thank you. Because we want to make sure that this is accessible and a lot of it accessible.

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Exactly.

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Steve, I wanted to ask you about in, a number of patients asked about this too, when you're diagnosed. In...

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most of us, not all of us, don't need treatment at the time. We go into active surveillance or what is called watch and wait.



CLL SOCIETY

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But I remember having a sense, you're not going to do anything about this cancer. What can I do?

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To maybe make myself part of that one out of four, one out of five patients who never needs treatment or delay the treatment as long as possible.

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Are there any things that you thought about when you had the diagnosis or you'd advise your fellow CLL patient, understanding that everybody's biology is different and we're not going to necessarily make a difference, but what advice do you give to someone when they're diagnosed that there's no imminent therapy, maybe years off.

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Right, right. So it's a great question and it's a scary concept. If you're the one who has been diagnosed and not given up.

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Plan a path forward I think first and foremost. One of the main points to think about is if your physician is not warranting treatment, it's because you're not sticking up for your physician to want treatment, right?

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So take that as a win and celebrate that. I understand that it's on the radar and you need to watch this, but you're not at the point where you need to be treated.

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And the reality is that advancements and breakthroughs are coming fast and furious. So my perspective is the longer you can put off treatment...

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the better your treatment options are going to be when you're eventually doing treatment. In the meantime, I think it's important to just focus on a healthier you, right?

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Take the disease component out of it completely. And you know the diet, the exercise, everything that we've been talking about, they're still an opportunity to kind of fine tune yourself and get yourself in a better position.

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A, healthier in general but B, in a healthier spot if and when you know treatment were to be wanted at some point, but...

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you know what I hang my hat on the fact that the advancements are just crazy to keep up with and at some point when you're going to need treatment you're going to have some good options available to you.

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CLL SOCIETY

Doctor, the issue of sugar and sweeteners is a hot topic. And a lot of people said, well, what about natural?

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Sweeteners, stevia, agave. Honey and I would add being from Canada...

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maple syrup. I mean are these things any better than just you know cane sugar?

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I do think that there's some marginally benefit better data for these natural sugars.

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Even cane sugar, to be honest, is not something that I would say you know completely go without when I'm talking about sugars to avoid. Most of the data comes from the modified sugars...

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so things like the aspartame things like, you know, that are not still in the molecule's natural or original form.

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These are the things that I tend to tell people to avoid if you're a label reader. Those are going to include things like high fructose corn syrups, these sweeteners that are typically found in I guess the most common thing is going to be like our soda drinks.

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Things like that. I think if you are somebody who is a generally healthy person in your daily consumption of whatever foods you eat...

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including the natural sugars, honeys, maple, sugar, syrup, agave, and I think that is okay, you know, if you are an over consumer though and you know that you have a sweet tooth I would say that it's time to start bringing that down.

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The data is not 100% clear that all sugar needs to be avoided, but at least we do know that modified sugars should be avoided.

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And on the whole, we know that people with better nutrition do better when it comes to cancers including CLL.

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So high intake of natural sugars also should be minimized just for your overall health.

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Yeah, I would, tend to all things in moderation, including moderation, you know.

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Yeah.



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Everything is off on your birthday. You know, you can do whatever you want that one day.

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That's true. You get once a year.

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Steve, I think both of you touched on fatigue, and I'd be interested, Steve, in your sense of this issue as an athlete.

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Yeah, we know that exercising, even when you're tired, actually helps the fatigue, but do you have any tips on how do you do that?

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I mean, if you're tired, the last thing you want to do is put on your running shoes and go for a run or do something.

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Do you have anything that pushed you through any advice you could give, along that lines.

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Yeah, the two lessons that I learned pretty quickly from my oncologist is you know, to listen to your body because as an athlete you tend to have an idea of what you want to do right on any given day if you're training for something or you know you think you want to do go out and do a 10 mile run and...

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your body gives you a rude awakening a half mile into the run and says you're not doing this today.

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So I think the key is to be to be flexible and to be to be able to adapt and adjust. And you need to listen to your body at all times and you need to make those adjustments.

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But also importantly, you know, less is more. It doesn't take an hour strenuous workout to feel a benefit.

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You know, you can go out for a 10 min. vigorous walk to elevate your heart rate and feel really good and still get some benefits.

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So I think if you can, most are up enough ambition to just get the sneakers on or get whatever it is that you've got to do to get one foot in front of the other...

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even if it's a small increment of some kind of physical activity. That's good. Get things moving.



CLL SOCIETY

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You're going to benefit tremendously from it. And you may find that, hey, I feel better than I thought I was going to feel.

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So my 10 min workout just became a 20 min workout or whatever.

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Doctor, let me ask you one more logistics question.

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Is acupuncture generally covered by insurance and how do you find a good acupuncturist?

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Because at least in SoCal where I am, there's a lot of people who kind of do acupuncture.

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But how do I know if I'm getting, is there a board certification for acupuncture to help us and know that if people want to go down the traditional Chinese medicine path.

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Yeah, so there actually is. A college quote unquote, of awarding certification to acupuncturists.

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So you should definitely look into somebody who is licensed and well-trained when it comes to utilizing things like acupuncture.

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If you come across somebody, definitely ask them for their certifications. I can't think off the top of my head right now what their governing body is called but they're just like most other practitioners whose job it is to take care of people.

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It really is something that, is also, you know well, what's the word? Well kept track of you know so you shouldn't often run to somebody who is a sham acupuncturist if that makes sense.

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When it comes to insurance, there are so many hidden benefits that a lot of insurance carriers have that I've been learning more and more about as I went into the world of integrative medicine so much so that people definitely need to reach out to their insurance companies and say, hey, what's the supplemental plan?

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What supplemental treatments can I, can I utilize that you cover? Because for whatever reason they don't advertise it, but they do cover it.

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I know for example, and just more personal, I have Blue Cross Blue Shield and there are some acupuncture benefits that are provided in that as well as massage therapy and things like that.



CLL SOCIETY

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And then completely unrelated, recently had, I recently had a baby and found out that, you know, a lactation consultant is covered and occupational therapy for babies.

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There are so many things that your insurance likely covers and it just takes again, just that taking that first step.

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Calling them and and asking about it. The other thing is also discussing this with the practitioner, the acupuncturist.

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They will be the ones that will likely know where to point you. In the direction either of advocacy groups or even based on your insurance, what questions to ask when it comes to coverage.

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Unfortunately, I do know that not all insurance have this benefit, but it's also worth, you know, asking your insurance company what coverage you might have.

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You mentioned massage and I'm going to ask both of you to talk about that. Maybe you can start, Doctor, but is massage safe with the CLL patient.

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Patients worry, maybe they have swollen lymph nodes.

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Should the massage servers stay away from the lymph nodes? It's a disease in the lymphatic system.

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This is a problem to get a massage. What, where do you see the role? And then Steve, maybe you can comment as an athlete.

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You know, I know that when I work out, I get pretty sore muscles and I get massages.

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I just wonder how much you see that as a role too. So maybe you can start, Doctor.

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I don't think, massage is absolutely contraindicated in people with CLL.

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I actually think it's quite beneficial for the most part. And so, if it's something that you're interested in, I do encourage.

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I think the things that need to be looked into are more so your platelet count and your red blood cell count at the time of engaging in massage therapy.

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As some of you will already know, one of the treatment indicators for CLL is if your platelets start going quite low and your platelets work hard to keep your body from, you know, experiencing bleeding issues and bruising issues.

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And so massage is, particularly deep tissue, can be quite problematic in in that sense. So I would say if your platelet counts are trending down, typically we say, you know, less than 100,000, less than 80,000.

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I would probably stay away from massage during those time periods. Now, when it comes to lymphadenopathy, those enlarged lymph nodes, I think it's important to point the massage therapist onto those areas so that they are aware of it so that they simply avoid those areas when they are performing a massage.

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But no, I think if it's something that is helpful to you, if it helps you feel better, I don't think it's problematic.

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Those are just the two things I would make sure that you are aware of, that your platelet count are usually above 100,000, you don't have severe anemia and they avoid the areas with lymphadenopathy.

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Steve, anything you want to add to that about your experience with massage?

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100% fan if I could hire a living massage therapist, I would. Yeah, I just think it's beneficial in so many accounts and the only thing I'll also add is if you're new to massage, you're going to want to increase your, we should all be drinking, a lot of water anyway but you typically want to increase your water intake post massage because as your is releasing some of the

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Toxins, it's you know, it needs a vehicle to keep moving so that's my one little tidbit I would add to that.

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What I might add too, just reflecting on what said earlier, my insurance doesn't cover massage, but I have a flexible spending plan and getting my doctor to write a referral that I would benefit from massage therapy, then at least I'm using pre-tax dollars instead of post-tax dollars on that.

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So that can be a help too if you, if you plan that in advance. Steve, people ask about performance in just, did you notice in that drop in your performance that before your CLL and how was that



CLL SOCIETY

responded, if you noticed, that it's gotten better as your CLL has gotten better or how much of a performance issue is that something as an athlete you can use and say oh my CLL may...

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be taking off because my performance is down or it gives a sense of that.

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I'm assuming this is Nate's question because I've been staring at this comment at the bed hoping we got to it.

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So how I feel performance wise has actually turned into one of the first discussion topics I have when I check in with my oncologist every 3 months, right?

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We have the normal discussion that we always have and regardless of what the lab says, he'll ask me how my runs are going.

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You know, he wants to know what is what, is the forget what the what the lab is saying well what is the impact on your daily living.

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Right? What's what to do if you and I found several months before I was diagnosed, my exhaustion was through the roof and I remember being in the middle of an extremely challenging race in Lake Placid, New York, Ironman Placid.

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And it's a, if you're not familiar with, I mean, it's a 2.4 miles swim, a 112 mile bike and then, and then from 6.2 marathon.

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I remember being halfway through the bike. And just feeling like I wanted to close my eyes and go to sleep in the middle of the ride I was so exhausted.

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And it was shortly thereafter that I was diagnosed and, you know, things started to make a little bit of sense.

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But what I found was kind of getting back to my earlier point about listening to your body, is it's very cyclical, you know, my body will...

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wanna shut down and will not be as responsive during certain times if I'm having a flare-up, if I'm in the middle of treatment, if I'm depending on what's happening, but...

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if I take care of it, if I listen to it, if I dial back where I need to, it tends to come back in my, you know, my fitness levels.



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They have not significantly holistically dropped as a result of CLL. It will fluctuate. Over the course of weeks, months, years, but I've been lucky thus far.

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I need to be patient with it, but it usually comes back when I'm, when I continue to care myself and listen to what my body wants.

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5%.

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So you use your performance, it sounds like, also is a measure of where your CLL is at, is sort of it's it sounds like you're, you're not just looking at your, and you're looking...

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you know, what your training schedule is capable of and things like that.

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100% yes

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And very interesting and I think very helpful because that's part of the whole quality of life. Maybe you can comment on this.

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Right.

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A lot of questions about saunas, infrared saunas, dry saunas. I love a sauna, but any thoughts on health benefits from those?

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How you use that? So maybe I'll let you go first, Steve.

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I'm not opposed to them. I mean, it's not something that I work out or work into a regular...

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routine with you know, I usually enjoy them occasionally, but I don't I don't really feel strongly one way or the other.

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Do you think they have any therapeutic benefits, Doctor, or any contraindications for sauna?

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I don't think the data is out there, so I'm, I can't say, wholeheartedly, no, don't, don't do it.

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CLL SOCIETY

I think if it helps you feel better, I think it's something that you should, you should continue to do.

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The biggest thing when it comes to things like sauna and utilization of higher than average heat is going to be dehydration, okay?

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And dehydration can be such a hard thing to recover from, especially in somebody who has, a blood cancer, but harder still in people who are being actively treated for blood cancers like CLL, keeping in mind BCL 2 inhibitor venetoclax one of the biggest contra one of the biggest side effects associated with venetoclax is something called tumor lysis syndrome.

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It breaks down the abnormal white cells very, very quickly. And the way it does this can sometimes interfere with how your body gets rid of it and can lead to difficulty with your kidneys,

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expelling all of those cells. So my concern would be if you are going to be putting yourself in a sauna, a dry heat or a moist heat and experience muscle breakdown and you're on treatment that can potentially be problematic.

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So in and of itself I don't think it's a problem, but I do think you have to be vigilant if you are going to be doing something like that on treatment and probably wait to do it off cycle.

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Yeah, I would tend to agree, but I love a sauna. And, Let me follow up with the question too about chemo induced neuropathy.

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And I think this is one area where there's a little bit more research on some supplements that might be helpful, somebody is asking specifically about alpha-linolenic acid that I've read where vitamin E might be helpful for some patients and B vitamins.

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Do you have any advice for somebody who has a neuropathy, which is less of an issue these days with CLL because we're using less and less chemo, but any advice along that lines.

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My biggest, or what I've noticed to be the most significant, help in people with chemotherapy induced neuropathy is actually acupuncture.

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Wow.

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And as opposed to supplements, I think supplements are helpful. They've been you know, even some TCAs, antidepressants, things like that that have been shown to be helpful with chemotherapy induced, neuropathy but...



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the number of patients that I have been actively treating who have come to me in real time who are doing acupuncture, who come back saying, my neuropathy is either paused or my neuropathy is improving...

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with acupuncture. That's, that's now my go to that's what I recommend.

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100% of the time if you're able to get acupuncture that's where I send patients to.

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You touched on organic food. Somebody asked about grass fed meat versus regular meat and I would ask, you know...

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is cage free, you know. Eggs and chicken and this kind of stuff is all of this important to consider,

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you know, leaving aside the ethical treatment of animals, which I think is a whole other issue for just looking at the health issues.

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Do you have somebody wants to eat meat to have advice about how they do eat the red meat if that's important to them?

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Yeah, just like with the fruits and vegetables, I would say go towards that organic.

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Labeling for your meats as well, what the organic labeling on meats essentially mean is that these animals tend to be, as you previously mentioned, grass fed, they tend to not be given the additional hormones, the growth hormones, that non-organic cattle tend to be given and it also ensures that the foods that they are provided are also pesticide free.

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So for me, when it comes to CLL, it's pesticides, pesticides, pesticides.

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We've seen this in the data that exposure to pesticides increased risks. And we also see in what I would consider the biggest pesticide experiment, Agent Orange.

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You know, there's so many veterans who come with CLL who have had Agent Orange exposure, so for me, yes, if you can kind of limit the bad exposures that your animal and dairy foods have...

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that would be the optimal thing to do. So yes, if you can get a cage-free, you know, type egg situation if you can get a non-hormone added, grass fed...



CLL SOCIETY

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you know, type situation for your meats as well that would be the best choice.

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Yes

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Hey, can, can I just throw something in here real quick just because there's a lot of plant-based alternatives to meat products that are really, really, really good.

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And you might not know that you're not eating...

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the real thing, you know what I mean? It's oh, it's worth looking into.

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I've been pleasantly surprised just in experimenting with some different things. And getting some plant-based...

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alternatives to some meat products.

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Yeah, I'm plant-based as a lot of people know and haven't eaten red meat in two decades now.

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But I would say that there is a bit of a caveat to that, that it's better to eat broccoli than a fake hamburger that's heavily processed, that tastes a lot like a hamburger.

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And I've had these, you know, these without mentioning the brands or some out there that are delicious and I, and I have them occasionally but I'm not sure if it's that heavily processed.

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It's all that good for me. I mean, I think it's better to eat fruits and veggies that are fruits and veggies.

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I agree with you.

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And occasionally, occasionally, I want a fake pizza with fake cheese that's made from nuts instead of dairy and all of that, but I'm not sure it's all that much healthier than having a regular pizza which would probably taste better, you know, but it is an interesting...

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I mean, Oreo cookies are vegan, you know, Oreo cookies are not good for you.

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CLL SOCIETY

You know, plant-based ice cream isn't necessarily better for you than regular ice cream so I think that...

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I think you're hitting a very big point and something else that I see often in my patients outside of just CLL, just in cancer care in general.

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I'll have patients that, you know, come in and tell me, oh, I'm vegan, oh, I'm vegetarian and then I actually, you know, go through what are you actually eating and some people are just not eating good food at all.

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They're just avoiding meat. You know, so I think like you said, if you want a burger and you want to be plant-based, probably go for the black bean burger as opposed to the non, we won't say the brand name again, but heavily modified to taste like beef hamburger.

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Oils, I just again, both of you can comment, so you mentioned olive oil in the Mediterranean diet but there's certain other oils that are good for you and certain that aren't good for you.

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Somebody asked about coconut oil. I know I use a lot of toasted sesame oil for taste and stuff in food, do you have advice on oils beyond olive oil?

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Either of you.

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I think I prefer olive oil being you know the number one and then I do think if you are going to be cooking with other oils, I would prefer things more like non-blended oil, so single source type oil.

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So you mentioned things like the coconut oil and the sesame oil; I would avoid oil combinations because different oils have different boiling points and can create different types of, I forget the exact word I'm looking for, but they do end up creating...

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oxidants that may not be great for your body. I think canola oil in the grand scheme of things is considered a good oil over something like just a general vegetable oil.

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I think avocado oil is also considered a good oil as well. Again, all oils in moderation.

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As I mentioned, I focus heavily on nutrition and I think nutrition starts even before you put the food on your stove to cook.

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CLL SOCIETY

I think it also comes into play with what you're cooking with, what pans you use and so if you're able to utilize cooking pots and pans that don't require you to even use that much oil.

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That's also where I would, where I would start.

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Steve, you want to add anything to that?

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Good she hit on avocado oil as okay because we recently kind of stumbled on that and I've been, n I've been a fan.

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So I mean, you know, again, we'll use it in moderation, but...

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definitely olive oil and avocado oil or just even if it's just, just that on your cell or something...

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it's been a, you know, turned into a favorite for us.

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Those are my go-to oils, avocado oil and olive oil for cooking.

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Alkaline, water or you know when I was first diagnosed I read this book called alkalize or die you know, and is there any science behind that Doctor? Do you want to take that?

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I have not come across any reliable evidence-based or even evidence-informed data that shows drinking alkaline water changes overall survival or anything in any sort of cancer.

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Let me, let me push on a couple of other things here, just that are...

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I'm just gonna divert just for a couple of minutes, just some CLL specific questions that aren't, but I think they're important.

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COVID vaccines for CLL patients. How often should we be getting them? And what's your recommendation to your patients?

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I know that's not integrative oncology, but you are an oncologist and you CLL, yeah.

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Yeah. I think vaccinate as much as you can when the time is right. Typically, I think for COVID now we're seeing at least every 6 months.



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It's hard in CLL because CLL inherently targets your immune system and we have found that people just don't mount as high of an immune response as they may have prior to CLL and so people tend to have increased illnesses and so because of that I say continue your vaccination routines for sure.

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I think what is also important is to discuss evaluating your immunoglobulins with your oncologist as well.

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CLL, like I mentioned, can do a number on your immunoglobulin, on your immune system.

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And so you may end up finding out that oh, it's not that I just keep getting sick, you may have clinically diagnosable immunodeficiency related to your CLL and so that's also something to keep in mind, so yes, vaccinate when you can flu, COVID, etc.

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Be wary of overvaccination as far as, you know, I've had patients say do I need to restart my whole, you know, vaccination scheduling from hepatitis to this to that; not if you've had it and you were up to date on everything else.

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Then it's just going to be the, you know, annual semi-annual vaccines that you need to keep up-to-date.

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You know.

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And I've always gotten any vaccine that I could. My entire 18 years of living with CLL.

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And for some of them, I can even get in my own doctor's office when I'm there.

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Which brings up a great point about your immunoglobulin levels because I experienced that very situation last summer.

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In spite of being well vaccinated, in spite of taking all the precautions, I had just gotten pretty sick and couldn't shake it.

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Either bronchitis or pneumonia for quite some time. And my, you know, globulin levels had bottomed out...

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so we started on infusions of immunoglobulin to help bring everything back up in the...



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normal levels and since doing that, I haven't had any, I haven't had as much of the snuffle or anything, you know, being a good place.

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And I would say watch out at the CLL Society, we're gonna be, huh, looking at some trials and stuff that look at the role of immunoglobulins and maybe they're under usage in CLL and redefining other use because right now there's pretty strict criterion.

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They're very, very expensive. Insurance doesn't like to pay for them. So you have to have a low level of IGG that's documented and then you have to have...

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recurrent infections and respiratory infections to qualify for it.

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So we're looking to see are those too stringent, might it be better and there may be some clinical trials that will allow access...

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to that. A couple things and again I wonder on this do people have a favorite dairy substitute, like a nut milk or something like that that people like and should soy be avoided?

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That's, that's another question here. Either one of these can take that. Go ahead, Steve.

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I personally, I drink oat milk, not, it's not a nut base, but I enjoy it the most.

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I don't drink soy milk because more of a taste issue. As far as almond milk, I think it's fine, but I don't drink it more for the ethical issue as far as how much environmental impact it takes to make almond milk.

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But so I, I favor oat milk just because of those, those aforementioned things what about you, Stephen?

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I'm in the same boat. Yeah, see, and I do like almond milk but I'll try to limit it too. Also because a factor with the substitutes too that they can get, they can get kind of costly so drink it sparingly or put it in my coffee but oat milk as well.

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There was a ton of questions on specific supplements and I, I kind of stayed away from them because I think I know what the answer is going to be, not a lot of data you know but you know, I'm going to list a bunch and if you want to jump in and pull out one or two, like Zeolite was one that was mentioned.



CLL SOCIETY

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Ashwagandha. I'm, I'm mispronouncing that

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Ashwagandha.

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Mushrooms, medicinal mushrooms, including reishi was one that was mentioned.

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Omega three's I could go on and on, hmm.

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So I can touch on ashwagandha. Ashwagandha is an herb that is considered what we call an adaptogen. An adaptogen meaning that it tends to, you know, what might be lacking in the body might be able to help in that regard.

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It's got anti-inflammatory properties as well and immune properties as well. When it comes to the world of ashwagandha, we tend to have people who have autoimmune conditions limit their use.

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We also tell people who are pregnant or lactating to limit the use because there's not much studies on...

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them as a general supplement. I don't think it's a problem in CLL. The question in cancer always comes, in can I take this supplement to not get cancer or can I take this supplement to stop progression?

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And I always emphasize that at this point we have not found one thing that can change the course of someone's cancer journey, you know, so...

01:37:01.000 --> 01:37:18.000 the data is not there, but it's getting there You know., And so it's just gonna take some time when these clinical trials come up, it's important that not just the patients participate, but I'm also telling, you know, colleagues in the medical field.

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Tell your patients about these clinical trials that tend to be little bit easier to tolerate, you know, because the more people participate in trials, the more data we're going to have.

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Unfortunately, a lot of trials with supplements, this includes the ashwagandha, green tea extracts, curcumin, things like that...

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are based on mice models and things like that or sell models where you see the anti-tumor effect, but they are not quite ready for primetime.



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You know they have not been effectively studied in large human populations. And so everything in moderation but no there is no magic bullet that, you know, was going to effectively change the course of one type of cancer or cancer in general.

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There's a million questions I would love to have gotten to and I would have loved to have heard the answers for but we didn't get there so I'm going to just ask people for their final closing thoughts.

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I'm just going to share one thought I have and this I stole from an Australian surfer with who had prostate, disseminated prostate cancer and other people of that modifications but I say every day take your MEDS.

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In your MEDS stands for meditation is the M, E is your exercise, D it is diet and S is sleep.

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And if you take care of those 4 things, it isn't going to cure your CLL but it's already tough enough having CLL.

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You don't want to also have heart disease on top of it or diabetes on top of it or kidney damage.

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And if you do those things, you're going to tolerate whatever therapies. And we have such great allopathic Western medicine treatments for CLL.

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It's not like it was chemo or nothing like it was when I was diagnosed and when Steve was diagnosed.

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Now we have great options to treat CLL that are very non-toxic. So, I think we have great options.

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So let me let you go first, Steve, and then I'm going to let you wrap it up Doctor, in terms of any final thoughts that you want to share.

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Yeah, I think the one thing I'd like to reiterate with folks is just the importance of kind of managing this down on a micro level because if you, you know, you get a diagnosis and you try to wrap your head around what does it all mean?

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What, I need all the answers today, right? I, I need my treatment plan, I need to know how I'm going to respond.

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I need to know whether my hair's going to fall out. I need to know all these questions. You're going to come un glued, right?

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So what I've learned is that just managing it, microscopically, step by step. I use a lot of times I'll use the endurance sports analogy, right?

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If you're, if you're standing at the start line of a 26.2 mile marathon and you try to wrap your head around 26.2 miles,

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it's not going to be a very emotionally healthy place to be, but if you just think about I'm just running water stop to Woodstock or Walmart or to mile marker,...

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you just got to get through the little...

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So doctor, the last words are yours, go ahead.

I think one of the special things about CLL that we don't often see in other cancers is the watch and wait.

A lot of people with other cancer diagnosis. Ask me at the time of diagnosis what lifestyle changes can I make that will either make this cancer go away or change things and in those situations when we think of things like pancreas cancer or you know cancer, there's not a lot of things that you can do in that moment, reverse the course of the disease, but with CLL, especially because people can have years and years of watching wait this is a time where you can really start to utilize these.

Integrative medicine practices. These lifestyle changes and these dietary changes, increasing your activity really being mindful about how you treat your body how you take care of yourself what you prioritize and so I think that is going to be my final word.

My take-home message is if you are in the watch and wait. Of CLL and even if you're not but if you are, this is the time you have a time that a lot of people with cancer don't have to work on taking care of your whole self so that's gonna be my recommendation to you.

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Wonderfully said, I think about this and I would add it's not only the active surveillance or watch and wait period, but a lot of the therapies are long, I mean most therapies at least one year and some people are on a BTK inhibitor for years and years some 7,8, or 9 years all of this time, what can you be doing to supplement to make it more effective to keep yourself healthy so I think it's you know it's a marathon, not a sprint.



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I think Steve would appreciate that so in closing I'd like to once again, thank our generous donors and grant support from Astra Zeneca for making this possible. Thank you all for joining us today and a big thanks to our speakers, I mean they were great.

Please do our end of event survey and provide your feedback. We really do pay attention to that.

This was recorded and will be available on the website along with the slides and a transcript. If your questions weren't answered, send it to ask the expert all one word at cllsociety.org (asktheexpert@cllsociety.org).

Save the date for an virtual event ask me anything with Dr. Deborah Stevens on April 11 that's going to be a fabulous event please remember the CLL society is invested in your long life and you can invest in the long life of CLL Society by supporting our work.

Ron shared CLL Society's research grant on integrative oncology as a matching campaign so your donation is worth double for this unmet need CLL and believe me there's almost no sponsorship available nowadays for integrative oncology research and CLL also were really proud to be doing that.

Thank you all very much for your attention and for attending.