



CLL SOCIETY

## Webinar Transcript

### Navigating CLL with a Comprehensive Wellness Approach

April 17, 2025

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

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

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because we believe smart patients get smart care. As a reminder, you can rewatch all of 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.

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At this time, I would like to introduce our moderator. Thank you.

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Thank you, Robyn. My name is Larry Marion. I'm a 20-year veteran of CLL, a patient advocate, a member of the CLL Society's Patient Advisory Board...

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and co-facilitator of the Boston CLL Society Support Group. I would like to welcome you all to today's event.

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We are joined by our speaker, Dr. Deborah Stephens. She is Associate Professor of Medicine, Director of the CLL and Richter's program at the University of North Carolina at Chapel Hill.

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We will be answering audience questions at the end of the event...

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so please take advantage of this opportunity and type your questions in the Q&A box.

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Before we begin, I'd like to share a few important disclaimers.

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The information provided during today's webinar is for educational purposes only,...

00:12:38.000 --> 00:12:48.000 it should not be considered medical advice. For any personal health or treatment questions, please consult with your healthcare team.

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Also, please note that while the CLL Society may have its own opinions and policies,...

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our speakers may offer differing viewpoints, especially regarding management of CLL and its complications.

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Now it is my pleasure to welcome Dr. Deborah Stephens.

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Hi, my name is Dr. Debbie Stephens and I'm the Director of the CLL and Richter's program at the University of North Carolina at Chapel Hill.

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I'm really glad to be here with you today speaking about a very important topic, which is navigating CLL with a comprehensive wellness approach.

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Today I'm going to be talking about a few things, including what is integrative medicine,...

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a little highlight on cancer-related fatigue, the impact of exercise, stress,...



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diet on CLL and the use of supplementation. And so first, what is integrative medicine?

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This is an approach to healthcare that combines traditional medicine with complementary and or alternative approaches. And a few examples of this I've listed here, including mind and body therapies like yoga, meditation or acupuncture,...

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biologically based therapies like herbal supplements and diet and nutrition,... manipulative and body-based techniques like massage or chiropractic or osteopathic care and different energy related therapies.

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Integrative oncology is the specific practice of using integrative medicine in the healthcare of patients who have cancer.

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And so today, a lot of the topics are going to focus around this. And I think a really important topic to start with is cancer related fatigue.

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The reason why this is so important is almost every single one of my patients has some level of fatigue...

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and is a really common symptom in people with CLL. And at times, it's the only physical symptom people have.

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Fatigue in CLL is not usually alleviated simply by resting. And it's really thought to be related to chronic activation of your immune system that occurs with CLL.

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My best recommendations here are good diet, hydration, and physical activity to help alleviate this fatigue.

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I'm going to be talking a little bit more in detail about this on the upcoming slides.

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You know, one thing people always ask me, is there some sort of medication I can take for my fatigue? And the answer is, unfortunately, not really. One study that highlights this was a meta-analysis of 113 studies that revealed that pharmacological treatments or medicines, a lot of these, do not improve cancer-related fatigue.

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But exercise and psychological interventions do have a really positive effect. And so, I guess the summary is there is no magic pill for this.

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And it takes some balance to alleviate this cancer-related fatigue.

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Let's talk a little bit about exercise and the immune system...

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and a lot of the studies that I'm going to highlight today include a small amount of patients or patient samples, and they show associations.

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And so, it might not necessarily mean that any of these things are causative, but there's an association or correlation.

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So, in terms of exercise, there was a small study done with patients who had previously untreated CLL...

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and the study investigators classified these patients into categories of fit versus unfit based upon some physical testing that they did as part of the study.

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Then they collected samples out of these patients and they did studies of the plasma, which is the liquid part of the blood without the white or red blood cells,...

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and showed lower levels of inflammation and higher levels of mature or functional immune cells in the patients that were classified as fit.

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Additionally, when they took this plasma or the liquid part of the blood...

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of the patients who were considered fit, and they mixed it basically in the lab with CLL cells, the cancer cells grew more slowly than they did with the plasma of unfit patients.

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And so again, this is not a clear causation, but there are data to suggest that exercise may boost immune function...

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which could slow CLL growth. Of course, a lot more data is needed here but exercise is good for you in many ways.

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And I think this is just one way to highlight how important it is to exercise in folks that have CLL.

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What about the impact of stress? There was a study of 96 patients who had CLL who were receiving ibrutinib, which is an oral anti-CLL therapy, for a relapse of CLL.

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Patients who were deemed as having higher stress levels in this test had evidence of immune system overactivation and increased markers of inflammation...

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which is also associated with the higher number of CLL cancer cells.

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And so again, this shows an association, maybe not a clear causation or anything like that, but it does suggest that higher levels of psychological stress may negatively impact your course of CLL.

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So what do you do about it? Stress reduction. I already talked about exercise. This is really important because it improves mood,...

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reduces anxiety and enhances your overall well-being in terms of other medical conditions as well.

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Really important to do the things you like to do so hobbies and activities you otherwise like, find the time or find the way to do these sort of things.



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Also, relaxation techniques and mindfulness meditation and journaling are very helpful.

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And if you have a smartphone, checking out your app library, because a lot of these things like yoga, meditation,..

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journaling, deep breathing; there's a lot of times there's apps that either remind you to do these or they help to guide you through some dedicated relaxation.

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Social support is really important for stress reduction. This means connecting with friends, family or support groups. And one of the things, one of the many things that the CLL Society does really well, is get people together with support groups. And so many of you likely know if you look at the CLL Society website, you can find instructions on how to sign up for a support group, either near you or just a group of like-minded or similar situation patients.

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What about acupuncture? This is a traditional Chinese medicine technique that involves inserting needles into specific points on the body.

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The goal here is to stimulate nerves and promote healing.

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One thing that's nice about acupuncture is there's no drug interactions. These needles are also very small. So even those of you who are taking things like BTK inhibitors that can increase bleeding and bruising,..

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are still able to do these techniques. When you look at all cancer-related treatments, the evidence is the strongest for reducing pain and nausea and vomiting, but there is some evidence to support relief of peripheral neuropathy,..

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fatigue, constipation, insomnia, night sweats and pruritus or itching in cancer patients.

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So, moving over to a topic that is very much discussed in my clinical consultations with folks, is about diet.



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And these are some of the questions that I get but I'm sure that there are a lot more out there, which we'll get to in the Q&A portion.

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Some of the questions are: was this CLL caused by a bad diet? Is there something I can eat to fight CLL? Should I cut out sugars? Do I need to eat organic foods only?...

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and really importantly, are there any supplements that I should take?

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So again, there are not a lot of great studies about this. There are some studies with associations or potentially cancer in general...

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which I'm going to try to highlight things that specifically focus on CLL. But I found just a general study on dietary factors.

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And in this study, they found that dietary factors are among the leading cause of death in 195 countries, including the United States.

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They looked at many dietary risk factors, which I've listed all here, but the ones that they highlighted as most important as causing a risk factor towards more likelihood of death where high sodium intake, low intake of whole grains and low intake of fruits.

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Now, again, this is not specific to CLL. It's just talking about dietary habits in general...

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and how to prolong people's life through what they eat. So another study, that was completed in Spain, found that a Western style dietary pattern was associated with the risk of CLL.

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And what do they define as a Western style dietary pattern? They said this is one with a high intake of high fat dairy products, processed meats,...

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refined grains, sweets, caloric drinks, convenience food and sauces.



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So again, this is kind of an association but it doesn't say that CLL was caused by this. There's likely lots of other factors that we aren't able to quantify that are playing into this. And so, when someone asked me, was it my diet that caused CLL?

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My answer is always no, because it's unlikely that diet is a sole factor leading to causing CLL.

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And there are just multiple factors, including genetic factors, environmental exposures, lots of things that play in.

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So what about sugar? There are some data with higher fasting insulin levels that are associated with an increased risk of recurrence and death in breast cancer, but the data is less clear in blood cancers.

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Sugar present in natural foods doesn't appear to be problematic but there's some mixed data, which I'm going to go into, that suggests that consumption of added sugars and sugary beverages like artificial sweeteners can affect treatment response or risk of relapse in certain types of cancer.

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What about artificial sweeteners? I get a lot of questions about this. Do they cause cancer? Can they make my cancer worse?

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And this is really important because a lot of people with cancer or CLL try to decrease their sugar intake and end up increasing the intake of artificial sugars.

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And so, I wanted to put up some data about these artificial sweeteners and I just included some of the most common ones that are used. This is by no means exhaustive...

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and you'll find that the data are not really very conclusive one way or another.

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So aspartame is the most common one that I get asked about. This is the sweetener in Equal...





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or NutraSweet. There was an initial study done in rats that found that high doses of aspartame were associated with an increased risk of leukemia and lymphoma.

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However, later the investigators came back and said that the study design was not perfectly done and really the results of this have mostly been dismissed.

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How about in humans? Are there any data to support this? And a lot of this comes from a retrospective study or looking back at how much of these certain sweeteners were taken by certain patients. There was a 2006 study, which was a lot of patients, 500,000 individuals that found no link.

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A 2013 review of multiple studies found no link between aspartame and leukemia.

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Then there was this 2022 study of around 100,000 people who were followed in France for over an eight-year period of time,

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which found an association with increased aspartame and developing cancer. Now, this was not specific to CLL and there was a higher association with breast cancer and other obesity-associated cancers.

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And so in all likelihood, there are probably a lot of other factors other than just intake of aspartame that are playing into their risk of cancer.

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So what about sucralose? This is the sweetener found in Splenda.

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There was a study in mice that suggested consumption of high doses resulted in a greater risk of blood cancers.

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But I just want to note that this was actually done by the same lab as the aspartame study that is listed above. And so again, some of the validity of this test has been questioned and this also was a compound studied in that same 2022 French study and did not find an association with causing cancer.



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However, there was a lot less intake than intake of aspartame in that study, and so that may have impacted the findings.

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What about saccharin? This is found in Sweet and Low, Sugar Twin and Necta Sweet.

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There was a study in rats that found a relationship between saccharin and bladder cancer.

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However, subsequent studies have found that there's probably something specifically about the biology of rats and their bladders that led to this, so maybe not applicable to humans.

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That same French study of 100,000 people did not find an association with cancer, but again, there's less intake than there was with aspartame.

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So looking at these, I put up the FDA, their recommended maximum daily intakes, and I just wanted to go through a calculation with you to understand that in some cases, it does take quite a bit of these compounds to reach that max daily recommendation.

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And so just an example for a 70 kilogram person, that's about 150 pounds,...

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the acceptable daily intake of aspartame is somewhere between 40 and 50 milligrams per kilogram, which comes out to 2,800 milligrams a day or 3,500 milligrams a day.

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If you were going to take an example of a 12 ounce can of Diet Coke, this includes about 200 milligrams of aspartame,...

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and so if you were going to even follow the more conservative estimate of 2,800 maximum daily intake, you would have to drink 14, 12 ounce cans of Diet Coke per day.

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And so that's a significant amount of Diet Coke and so I would say again, I think that the data are still very mixed, whether there's any causation, whether this could make leukemia worse. I think anything in moderation is better than drinking, you know, for example, 14 cans of Diet Coke per day.

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You know, that's a significant amount of Diet Coke. And so just think about what you're eating on most days.

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And I would say just be aware of what kind of sweeteners are available and make sure that you're not going over those recommended daily intakes.

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What about organic food? So organic foods are foods produced without synthetic chemicals or fertilizers, pesticides, genetic engineering, or radiation.

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And again, there are some associations and some research has shown that several pesticides are carcinogenic.

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In fact, research on occupational pesticide exposure, a lot of you have heard of this...

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has shown that there's an association with the pesticide residues and increased risk of Non-Hodgkin lymphoma, just similar to CLL.

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There was a study done that high organic food intake has been associated with a decreased risk of developing Non-Hodgkin lymphoma.

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Again, this is an association, not a cause, and there are likely other factors that play into this as well.

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And organic food is expensive, therefore the American Cancer Association, and other societies, have noted that for individuals with limited resources, it's actually more important to prioritize a diet rich in vegetables and fruits, even if they're not organic...

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than it is to limit those vegetables and fruits just because they are not organic, if that makes sense.

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Most important thing is getting in those vegetables and fruits. And I wanted to highlight that there's some data on which are most important to buy organic.

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So, there's a list called the Clean 15 versus the Dirty Dozen and foods on the Clean 15 list don't necessarily need to be purchased organic, but on the Dirty Dozen, you know, would try to suggest purchasing them organic when possible.

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I've included those lists here. The Dirty Dozen is listed here on the left, again, those are the things that should likely be purchased organic if you're able to.

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Those include a lot of berries, apples, nectarines, grapes, green vegetables like spinach, kale,...

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green beans, pears, peaches. You can see over on the Clean 15 list, and these are ones that it's less important to purchase them organically, and you can see the list of about 15 there...

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listed. So what should you eat? There's a lot of debate on this, but I would say in general,...

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a Mediterranean style diet may be a reasonable aim to approach.

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This includes lots of plant-based, minimally processed foods such as fruits, vegetables, whole grains,...

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nuts and legumes. Principal source of fat in this diet is olive oil.

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You can eat cheese and yogurt in low to moderate amounts.

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Eating fish and poultry can also be consumed in low to moderate amounts.

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Red meat should be consumed infrequently and in small amounts and for dessert, using fresh fruit and trying to limit sweets, especially those that contain added sugars.

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So supplements, this is a big question that I get. Are there any supplements that I should be taking?

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And again, I will say that the data are very mixed on this, but I will highlight things that I think are quite important.

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I think one of the best studies that have been done in supplementation is the study done on green tea extract or EGCG.

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This is a study done at Mayo and they used 200 milligram capsules of this compound. And just a note that this is not currently available to purchase,...

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the specific one that they used. And also keep in mind, they use a dose of 2,000 milligrams twice daily. And so, if you do the math there, that means 10 of these capsules, twice daily,...

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for six months. This was a study done in 42 patients.

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There were some side effects: nausea, diarrhea, some evidence of liver inflammation, mostly mild.

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Twelve patients actually had to discontinue therapy early. Three were because of side effects and three were due to disease progression.

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There was one patient who had a partial remission. So, pretty low overall response rate compared to what we see with our standard drugs, at only 2%.

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A third of the patients had a decline in their lymphocyte or white blood cell count...

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of over 20% for two months. Those who had enlarged lymph nodes, 70% of them experienced a greater than 50% reduction in node size.

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So, there is some evidence of efficacy. It's generally safe. However, again, you need to monitor liver function tests. You need to be aware of the nausea and diarrhea.

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And, you know, some people say, well, that's okay, I'll just drink a cup of green tea every day. Just keep in mind that this was a heavy extract and conservatively, it's about like drinking 22, eight-ounce cups of green tea per day.

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And so, maybe some good data, some side effects, usually not long-lasting responses with this.

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What about turmeric? So, curcumin is the likely active agent in the common yellow spice turmeric...

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which is used in many curries. There was one CLL trial that looked at this in 21 patients who had high white blood cell counts...

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and they received 2,000 milligrams of curcumin daily for six months.

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In general, this is well-tolerated and was safe. There was again some nausea and diarrhea.

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There were no responses, but four patients showed a 20% reduction in white blood cell count...

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but it did increase after stopping. So, for these two supplements, both green tea and curcumin are likely safe...

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with some activity, but the efficacy is really unproven and might be minimal so it's generally not harmful to take.

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Is it critical to take these things? The answer is no.

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What about vitamin D? There was a study looking backwards at 390 patients who had newly diagnosed CLL, seen at the Mayo Clinic or University of Iowa.

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Thirty to 40% were vitamin D deficient and they measured that as a 25 vitamin D level of less than 25 nanograms per ml.

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They found that those with lower vitamin D had shorter time to first CLL treatment...

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and a trend towards shorter survival. This study did not test whether adding supplementation could improve these findings.

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Another study looked at 3,400 patients with newly diagnosed CLL who were included in a population database in Israel.

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And during the observation period, 27% of these patients received a vitamin D supplement for six months or more.

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Those who received vitamin D had a longer treatment-free survival. And in patients less than 65 years of age, those who received vitamin D had a longer time to first CLL treatment.

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This study did not sequentially test vitamin D levels, so we don't know how much supplementation was necessary and if the levels improved and to what level.

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It may not account for people who are just taking over-the-counter vitamin D supplements that were not necessarily collected on this study.

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This was not prospective, meaning the group was not given a certain dose of vitamin D.

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And I just wanted to add a note of caution that kind of something similar happened for patients with follicular lymphoma, which is another type of Non-Hodgkin lymphoma,...

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there were some of these kind of preclinical associations with vitamin D there, but a prospective study was done and it did not show benefit of longer event-free survival when given in combination with rituximab.

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So, vitamin D supplementation may be associated with better outcomes, but again, there may be other factors playing in.

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And so is it critical to take this? I think generally it's good if your levels are low to supplement them.

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But does it make an impact on your overall CLL? Likely. What about mushrooms? I get asked a lot of questions about mushrooms.

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And I by no means could find information on everyone that I have been asked about, but I wanted to highlight some of the more common ones.

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People have asked me about AHCC, which is active hexose-correlated compound, which is a mushroom extract from several species of mushrooms,...

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this includes shiitake and shimeji. The extract was tested against CLL patient samples in the lab and was found to be toxic to the CLL cells and it did reduce the number of cells in the environment...

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that we're helping to support the CLL cells. When tested on a mouse model of CLL, the investigators found that it reduced the tumor load, so the amount of lymph node and spleen burden,...

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CLL SOCIETY

and it did increase survival of the mouse. They thought it made immune therapy like antibodies work better against the CLL cells.

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So, this hasn't been tested in a prospective clinical trial but it really does show some promise.

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What about other mushrooms? Like I said, there's an exhaustive list of mushrooms.

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These did not have any CLL specific data, but I just wanted to highlight a couple of things because they were featured in some research based on blood cancers.

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So, the Y3 protein from shaggy mane mushroom, there were some lab studies that showed killing of T-cell acute lymphoblastic leukemia. There was a cordyceps mushroom where there were various lab studies with leukemia cells but not CLL.

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I know the CLL Society was interested in this and ran a study with drinking tea from the extract and suggested a decrease in lymphocyte count.

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Again, I get asked about a lot of these others mushrooms listed here and in general, there's thought that they can have some benefit, but there's no specific data for CLL. They haven't been tested in a clinical trial.

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So, just please consult with your doctor before taking any of the supplements. We just want to make sure we're looking out for drug interactions.

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So, a summary of supplements. They're likely eating a balanced diet is probably your best option. Keep in mind that supplements aren't as closely regulated as drugs that are approved by the FDA for marketing.

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I want you to be critical of very expensive supplements and please don't break the bank because none of these supplements have been proven...

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to have great benefit for CLL. And again, ask your medical team about any potential drug interactions.

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One thing that's nice and you can use as a gauge of how good is the supplement, one of the groups, which is nice, is called US Pharmacopeia or USP. You can see over on the right hand side of the screen, there's a little,...

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a little round logo there that says that this company has verified the supplement.

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They do a nice job verifying that supplements are what they say they are and are manufactured in a good and respectful manner. You can see kind of some of the process that this group goes through. They look at the facility, they look at the process, and then they test the ingredients to make sure that they have the amount of drug that they say they do.

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So, this is not absolutely required, but one of the things to look at is if the supplement has that USP label, it's more likely to have the ingredients that they say they do.

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They also have a website, which I've listed down here below, which is [qualitysupplements.org](http://qualitysupplements.org)...

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and that you can look up supplements that you have and see if any of those supplements are USP verified or you can look up and say, hey, I want a vitamin D supplement, which one is verified and where can I find it? So that's a helpful resource.

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I want to conclude my lecture by talking about Dr. Google. A lot of you talk about this, and I know it's really easy to check and find things online.

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And I looked at, I thought that integrative oncology website had a great approach to this and I wanted to share some of their recommendations.

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First of all, question the source of the information. So, is it coming from a reliable source?



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You want to consider the website's editorial policies. Is it just something anyone can post or are the data reviewed before they're posted up there?

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You want to check the level of evidence behind the claims. So, if somebody shares a claim, I want you to look and make sure that that data is actually out there to support it.

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I want you to be aware of polarized and overly simplistic theories on cancer like natural chemicals good, synthetic chemicals bad.

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You know, there's likely lots of shades of gray in between those two.

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Watch out for logical errors. Again, a lot of the stuff that I showed you, it was correlation or association, but we haven't really found exact causes for a lot of these things and so, you know, when we say, you know, yes, this might be something that is good or something you should consider, it might not be critical to your cancer care.

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And don't forget that your medical team is there to answer your questions.

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I just wanted to conclude by reviewing some of the things we've talked about today, including the definition of what is integrative medicine,...

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a little highlight on cancer-related fatigue, how exercise, stress, and diet can impact CLL, and what supplements maybe to consider,...

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and how to review the data and make sure you're getting the right supplement.

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So, I thank you very much for your time today and I appreciate being with you.

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Thank you, Dr. Stephens. Great presentation, a lot of great information clearly presented. Before we get into questions, just wanted to let everyone know we've got about three dozen questions. We'll get to as many as we can.



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If we don't get to your particular question at the end of the presentation, there'll be a link to the Ask the Expert area.

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There's an email address. You can send your questions directly to the CLL Society after the event.

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No surprise, the biggest group of questions relate to fatigue.

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How to figure out is this fatigue related to old age because most of us are getting older? Is it related to the inflammation issues that you raised because of our blood counts, et cetera?

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Can you do a little bit of a deeper dive, Dr. Stephens, on fatigue in terms of how do we know what's what, is this old age? Is this due to lack of exercise? How much exercise will help? Is there such a thing as too much exercise? Some folks are concerned about that, there's some research about NKs...

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cells being damaged from too much exercise. Talk to us about fatigue, exercise, and diet.

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Yeah, all of these are really great questions. And again, I just highlight that if you're having fatigue, you are not alone.

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Almost all of the patients that I see have some level of fatigue.

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And I think this is always a hard question. How much of fatigue is related to CLL versus something else? And I certainly wish, I think if anyone could figure out how to do this to create some sort of biopsy that we could say, you know, 60% is from CLL,

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40% is from thyroid disorder, you know, something else, that would be so helpful because the reason why this is important is because there's often a lot of other medical conditions that potentially are contributing.



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And so, when somebody is telling me about fatigue, I want to try to rule out those other medical causes. And so, you know, because there are some things that are easier to adjust than others.

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For example, I'm generally checking people's thyroid levels because if people have low thyroid,...

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you know, supplementation can really help with that fatigue. I'm often asking people for symptoms, looking for sleep apnea, because if you have sleep apnea,...

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potentially getting treated for sleep apnea can make a really big difference in your fatigue levels.

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A lot of folks have low testosterone levels. Gentlemen have low testosterone levels and that has to be checked at a specific time of day, has to be checked in the morning.

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And sometimes, in certain conditions, I recommend getting supplementation of testosterone to help with energy issues.

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And there's lots of other things like, for example, you know, stress and anxiety and even depression can cause fatigue as well. And I mean, that's just a hard mix because, you know, when you've had a diagnosis of cancer and,

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you know, different people have different tolerances of watch and wait or different side effects they're having.

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And so, you know, making sure that you're doing things to help stress reduction, you have good social support.

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Again, I would just advocate for the support groups that are run by the CLL Society because I found so many patients are able to meet other people that have CLL so they can kind of commiserate or celebrate together.



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And so, I think it's really tough to determine how much is exactly due to CLL.

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And one of the things that I always talk about, because sometimes that's the only symptom people have,...

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and when I say, how severe does fatigue need to be in order to do treatment for CLL because sometimes treatment of CLL can relieve that fatigue.

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I'm pretty cautious about that though because a lot of the treatments for CLL can have fatigue as a side effect. And so, if all of the fatigue wasn't due to CLL and we tried treating the CLL, you might kind of double up on that fatigue with adding some side effects.

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And so, um, you know, I, it's a tough science.

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You know, it's more of a feel and, you know, trying to eliminate other causes of fatigue, trying to encourage exercise, stress reduction, things like that in order to try to help folks with fatigue. You know, I mentioned exercise, how much exercise do you need to do?

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You know, this is probably pretty dependent on an individual patient.

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Because, you know, some people have certain physical restrictions that others don't.

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And so, but I would say, you know, in general, the WHO recommends about 150 minutes of moderate intensity exercise in a week.

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They do also recommend two sessions of some sort of strength enhancing or weight lifting, weight bearing exercise. That can look a lot different for different people. Some people can go to the gym and lift weights. Sometimes this is going to need to be something that is sitting in a chair and physical therapists or physical medicine and rehab folks can really help...

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to get an exercise routine that makes sense. And then I think the other part of the question that you asked was...

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is there such a thing as too much exercise? You know...

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the answer is, the answer is I'm not sure and maybe. You know, there's some evidence, as you mentioned, that really intensive exercise could cause some impact on NK cells. These are immune cells that live in your body that help to fight off...

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different viruses, they help to fight against different cancers like CLL.

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But, you know, there's a fine line because some moderate levels of exercise and even some intense levels, they actually release those NK cells from the bone marrow and help them to work better.

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And so, there's kind of a fine line. And so, I would say you know, do you have to be a marathon runner, which would be an extreme example. No, you don't. And I mean, I don't know what level of intensity...

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is the level you can't reach. But I will say that most people in their day-to-day exercise are not reaching that level of intensity. And so, I think, you know, more power to you, the more you can do, I support it.

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One of the other parts of the fatigue question is always diet.

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Should I just be drinking a lot of coffee? Chow down on chocolate? Look for caffeine wherever. What are your thoughts about this? It's temporary. It doesn't really help. Any port in the storm?

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What do you think?

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Yeah, I mean, this is also a little bit tricky too.



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Determine what part of your diet might enhance your level of energy.

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And I would say in general, I mean, we talked about an example of the Mediterranean diet, you know, that's just one example of kind of a good balanced diet.

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I think if people are eating a lot of really processed, heavy sugars, a lot of sugary soft drinks, a lot of fast food types and they switched to a Mediterranean diet, almost always people tell me how much better they feel, how much more energy they feel.

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And then there are some kind of little nuances of some people who have intolerance to things that they don't realize. Like, you know, taking gluten...

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or dairy, for an example. And so sometimes if people are interested in playing around with this, I'll set them up with a dietitian or a nutritionist.

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And say, you know, like, let's do a week or some period of time of elimination diet.

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Let's cut all the gluten out and just see how things go.

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And then if nothing changes, okay, that's not going to impact it so let's go back and let's cut out dairy,...

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see how that impacts you. And, you know, so sometimes you can do these elimination diets and you can find certain things you know if you're really, you know, pay attention, you know, journal during that time.

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Pay attention to those whatever side effects or symptoms that you're having and so it probably is not the same for everybody. I do think diet can help you generally feel better. Of course, it's good for other things like heart health and diabetes and all of that...

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which generally make people feel better. You know, caffeine, I don't have a problem with, although one thing I would caution is too much caffeine, of course, it can cause irregular heart rhythms and different things like that, anxiety sometimes and difficulty sleeping, which then makes you more tired, right? But, you know,...

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I think some caffeine is fine. A lot of coffees and teas are great. Just again, be careful what you're putting into your coffee and tea because, you know, sometimes people have like this much coffee and like this much like syrup sugary drink or something mixed in. So, you know, not all coffees are created equally either.

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But I don't have a problem with caffeine and just keep in mind that if you drink it too late in the day, of course, that's going to impact your sleep patterns too.

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Thank you, Dr. Stephens. Let's talk a little bit more about diet, not so much in fatigue, but related to CLL.

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There are a whole bunch of questions here that relate to, as you pointed out,...

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cutting down your dairy. Well, what impact does it that have on your bones?

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Maybe supplement with calcium? Maybe there are other things to do? So let's talk about diet. First, we'll hit the calcium issue and the dairy issue. Then we'll talk about some other aspects of diet and CLL.

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Yeah, that's a great question. And usually there's other ways to get calcium if you, you know, if your body's doesn't tolerate dairy or if you're cutting it out for other reasons. You know, you can, there's different products, you know, just even, you know, white beans and, you know, certain vegetables have calcium as well. But, you know, if you're cutting that out and you go to something like an almond or a soy milk, those are often...

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heavily fortified and actually have more calcium than cow's milk in them usually. So, you know, check the labels. You know, you can also get, you know, I'm cautiously saying this, I mean, there's orange juices that are fortified with calcium too. I'm being cautious about that because obviously orange juice has a lot of sugar in it too.



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Just being cautious about that. But even some breads are fortified with, you know, calcium and vitamin D.

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And so, you can find other ways or just taking a supplement, you know, find, you know, find one of those approved supplements and take a calcium vitamin D supplement to get around it.

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An aspect of diet comes up in the context of diarrhea.

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Lots of our CLL medications cause the runs.

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My own HEMOC said, "just take low Imodium".

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Maybe there's a better alternative fiber. Talk to us about fiber in general and in the context of the CLL patient dealing with diarrhea.

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Yeah, I mean, again, this is going to be pretty individualized and definitely it may take some experimentation to figure out exactly what works best for each person, but you know, yeah, using low Imodium can sometimes relieve those side effects.

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You know, fiber, again, it might take just a trial of fiber because if you're going from having no fiber to a lot of fiber,...

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you might have a lot of gas and cramping and bloating actually, so you know, maybe you're kind of creating another problem by it. But to get around that, you know, you can kind of slowly increase the amount of fiber because generally it does help to bulk up the stools and can be good for you in general.

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Again, when you think about, you know, thinking about elimination diets, things like dairy can sometimes cause more inflammation, gluten. Even some people have intolerances to eggs or other things that they're not realizing that are also contributing to having diarrhea along with it.



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Speaking of avoiding things, there are some folks who are vegans or vegetarians. Maybe they're not getting enough iron because they're not eating enough red meat. They're not eating any. Talk to us about from a vegan/vegetarian point of view

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How do we offset the loss of nutrients may be helpful in a CLL...

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situation.

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Yeah, iron is an important one. Protein is important. And so just speaking of protein, a lot of, you know, beans or legumes like, you know, green beans and other vegetables are good there, even spinach and broccoli. I actually have some protein that can be used for supplementation. Of course, all the nuts...

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have some good amount of protein in it. You know, you can use the soy-based products like tofu or tempeh and things like that. So, there's ways to offset that.

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In terms of iron, that can be a bigger deal for folks...

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and may require just some supplementation with, you know, supplements that you can buy over-the-counter.

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People don't always tolerate iron supplements by mouth. Those can cause some GI issues as well. Or, you know, I found some patients have had, you know, maybe you've had a weight loss surgery that has made some areas of the stomach are unavailable for absorption of these.

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This is something, if somebody who has CLL comes to me and they have anemia, I'm always going to check their B12 levels and their iron levels before I automatically assume that it's from CLL. And I usually try a trial about a month or two of oral iron supplements...

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and if that is just not working for them, they can't tolerate it,...



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it's not increasing the iron levels in their blood for whatever reason, there's several different formulations of IV iron.

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That you can do and it can bump up your iron stores really quickly. And it's pretty impressive the changes you see in the blood counts too.

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There's these cells called reticulocytes that are brand new red blood cells. And you can pretty much immediately see in somebody who is iron deficient, you see a bunch of these new red blood cells and then the anemia starts getting better. And so, you know, that's one way to do it if you know some people just,...

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also just don't have the ability to absorb these and may just need to take supplements of them.

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Excellent. Thank you. Here's a big picture question Dr. Stephens. Suppose someone listening to this says, okay, I want to contact an integrative medicine practitioner.

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Get, do a little drill down on my situation. How do I find one?

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I just discovered that Dana Farber has a department on this.

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You know that I found that out by accident. How do you find somebody?

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Yeah, this is a great question and I think it's going to be a little bit different depending on the area you're in.

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But I would just start actually, by you know, one thing you could do is ask your physician that they may know of a reputable group in the area. The other thing is whatever center you're being treated at or you know, whatever center that's...

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close to you, you use the example of Dana Farber, you know just Google Dana Farber Integrative Medicine...



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and see what comes up because you may find a group there. Most cancer centers are going to have some sort of patient resource like a library or, you know, something like that and, um, and in that case, they usually have connections to Integrative. They may have some, for example, they may offer massage, they may offer acupuncture, you know, right at the cancer treating facility.

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Another good resource is, you know, just have your doctor connect you with a dietary nutrition person. A lot of them can help either connect you to integrative medicine or help adjust the diet based on what symptoms you're having.

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We've gotten several people asking a question that's close to my heart.

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How much booze is too much? Let's talk social drinking, whether it's wine or hard liquor in this context, anything we should be thinking about?

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Yeah. Yeah, I think that's a great question. And I'm getting that question more often now too.

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Just given, you know, I think for years we had, you know, when we talk about the Mediterranean diet or other things, you say, you know,...

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glass of wine or two a day, no big deal. It can reduce your risk of certain types of cancers. And then, of course, you hear research come out that says, well, actually, no, alcohol is going to increase your risk of cancer. So, it can be really incredibly frustrating to figure out what are we really supposed to do.

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And I would say, I would say a moderate amount of social drinking is fine. What is a moderate amount? The maximum, the maximum recommended is one glass of wine a day for a woman, two for a man. But really, if you add that up, you know, that's like seven glasses of wine in a week, which...

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based on the new data that there is some link for other types of cancers.



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With alcohol, you know, I think that that's probably a little bit on the high side for what I would recommend.

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You know, of course, drinking responsibly, it doesn't help to like not drink at all and then drink a whole bunch on one day. You don't get to like average it out over the years because that heavy load can be toxic to the liver and, ..

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you know, everything else you know, um, so I think that's a fine question. And I would say I don't know that we know the exact amount, like how much alcohol does it take to cause CLL...

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or is that even possible that that's a cause of it?

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And so, you know, I would just say to exercise caution with alcohol. A lot of people who are really trying to follow as healthy of a diet as possible are cutting that out anyway because it contains a lot of sugars, ..

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as well. But I would say, you know, just being cautious about it. Make sure you're not going overboard with it.

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I know that's not a very specific answer, but I don't know the answer. What's the right amount?

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You know, everything is a risk benefit ratio and it is not clear to us what the exact risk is, but there seems to be some risk there.

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Gaining weight in the context of CLL. Ozempic and a whole lot of other injectables, et cetera, being viewed as a great way to reduce. Any concern about someone who's a CLL patient, maybe staying away from those things or maybe they don't matter - independent - what what's your view on that?

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This is a great question and I'm just going to start out by saying I feel like I may be a little bit biased on this.



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But I'll tell you where I'm biased. You know, it's a fine balance because, you know, we're always saying, you know, lose weight, lose weight. That's going to help you be healthy.

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And then, you know, here come these drugs that help people lose weight. And then we give them a strong skepticism, which is what I have of it.

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You know, I do just have a little bit of skepticism because we don't have that long of follow-up data with these drugs. And what does long-term use look like? What kind of risks are associated with that?

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I just don't know. I think we just don't have long-term data follow-up to say, you know.

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I don't have a specific reason why that would affect CLL, but it does impact the pancreas and I'm just not sure, I just don't love the trend that so many people are on these drugs right now without long-term follow-up data. I just...

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I really hope that we're not going to find out in the future that there's a bad side effect of them.

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And so, you know, I think the best way to lose weight is diet and exercise.

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I know some people say, I just need that boost to get, you know, to get going.

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And so, I'm not saying they're bad. I'm not saying they cause cancer. I'm just saying I feel a little cautious about them because I don't know what the long-term effects of them are.

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There's a bunch of questions that relate to inflammation and our vulnerability because our immune systems are in such bad shape.

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One interesting aspect is interesting people who are vulnerable like this, we tend to look for ways of avoiding respiratory infections.

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There are lots of, you know, the Emergen-C, there's lots of stuff you can take to avoid getting a cold.

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Mm-hmm.

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There are supplements, there are oil of oregano, echinacea, there's stuff out there.

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Mm-hmm.

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Any interaction make our CLL worse, no effect on our CLL, maybe help?

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Yeah.

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It's great to avoid getting an infection or you know. Anyhow, what's your view on those supplements dealing with infection, respiratory, colds, et cetera?

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Yeah, I mean, as you probably know, and some of you may be one of them, some people swear by vitamin C or, you know, other things. And so far, I haven't seen anything that is harmful to CLL patients, but I don't know that all of these supplements that you just mentioned,...

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you know, I think they're varied levels of helpful. You know, maybe it shortens a respiratory infection by a day or so. So maybe beneficial in that but, um, is probably not going to be the end all be all to keep you from getting infection. I still think...

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the very best way to avoid infections is to wash your hands and wash your hands well.

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Wash your hands often and try to avoid touching your face, you know, and just be aware. I mean, I know a lot of folks, you know,...





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especially with COVID and all the other respiratory viruses, they have questions, you know, can I go to a wedding? You know, can I be around other people?

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And, you know, it's a real balance because a lot of that stuff is good medicine too, right? You don't want to be isolated. I just spoke about having social support.

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So, I don't want you to miss all of your family's important events and otherwise.

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The most important thing to do is just wash your hands. Some people ask me about wearing masks and things like that. And I think all of it's a risk-benefit ratio. Of course, the closer the space you're in,...

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the more likely you are for someone else's respiratory particles to come in contact with you.

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And so, you know, outdoor or spread out venues are probably a little bit less likely that you're going to get that contact.

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But again, I think it's really important. You don't always get to set the venue. You don't get to pick where your niece gets married or whatever.

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And so, you know, just using good hygiene, I think, is so important and, you know, vaccines I also think are still important. They work variably well for CLL, but I do think they provide some benefit.

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The other thing is if you're getting a lot of respiratory infections,...

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your doctor might want to check your immunoglobulin levels because if your IgG level is low, it's possible supplementation of immunoglobulins can have a big impact on preventing you from getting infection as well.

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CLL SOCIETY

A question that comes up a couple times today that is very interesting. Let's go back to the stress, inflammation issues from our damaged immune system.

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Are you talking to some of your patients who have chronic joint pain...

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related to inflammation? Any recommendations about using CBD THC?

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Yeah, this is a great question. And of course, you know, CBD, a lot of the oils are available pretty broadly.

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Actual medical marijuana and other things or even recreational marijuana depends on what state you're in and so, I do think that they are helpful to a lot of patients.

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You know, there's some evidence in the lab that they do decrease inflammatory markers, you know, speaking of cytokines like TNF and IL-2, things like that. And there's even a little bit of data with blood cancers that CBD can decrease the number of cancer cells in your blood.

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But there haven't been, again, this is just an association, not a causal thing and, um, you know there haven't been any clinical trials that have shown, hey, take this much of CBD this many days a week and your CLL will be much better. None of that has been shown, but I do think it helps with joint pain. It helps with nausea. It sometimes helps with sleep.

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And so, you know, just so again, kind of what the supplementation piece that we talked about, not all CBD is created equal.

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So, make sure you know where you're getting it. You know, kind of what regulations, what kind of quality you're getting, um. Sometimes people ask me about smoking marijuana and I usually advise against that just because of the weakened immune system.

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If it is, if it's highly regulated, a medical dispensary from your State, that's probably a different story. And most likely, that is not the marijuana that I'm talking about. But if you



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grow it yourself or buy it that's not regulated, you just have to be careful because mold spores can live on those and if you smoke them, that's a,..

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that's a direct path of mold spores into your lungs, which of course can cause pneumonias. And so sometimes the oral formulations are a little bit safer or, you know, like I said, if you're in a State that has really regulated production, you know.

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I don't know, smoking probably still causes damage to your lungs, but I'm most worried about that fungal component in unregulated products.

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Yep, yep. When we're talking about supplements, B12, calcium, etc...

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some folks are concerned that how much is too much?

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Mm-hmm.

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Sometimes CLL patients are going to have higher than normal levels of say b12 Most packages recommendations specific dose But you don't know what else you're getting from other things. You could be taking a multivitamin plus this B12 or B supplement and all of a sudden you're getting four times the recommended level.

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Mm-hmm.

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How do you manage so you're not getting too much? And what level is too much? Obviously, it's going to vary by supplement. Talk us through how to avoid overdosing on these things.

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Mm-hmm.

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Yeah, yeah, great question. There are some vitamins that are called water soluble vitamins and all the B vitamins actually fit into that category. Same with vitamin C, that your body kind of regulates this on its own.



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And so, if you get too much of it in your diet or supplementation, you just pee it out...

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so your body kind of handles that piece of it. And so sometimes I tell people, you know, if they're taking too many supplements, they're just making really expensive urine, right? Because it's just, you don't really need that much of it.

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There are fat soluble vitamins like A, D, E, and K, and those you can get too much of because they, you know, they absorb into the fat cells in your body, so they're not quite as easy to get rid of,...

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you know. So again, I think if there's a question about a specific vitamin D, you know, we just talked about doing supplementation, those levels are really easy to measure. And so, you certainly can have your doctor measure those levels in your blood so you can gauge how high those are.

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And, you know, try to avoid levels that are much higher than recommended. I mean, the level that's considered a normal level is, you know, 25 to 30 or more...

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and that's the 25 vitamin D level. And so, you know,...

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staying above that number is good, but not, you know, the levels can tell you if you're overshooting...

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and that can be monitored with your doctor.

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You gave us an exhausting, you know, a pretty good list of all the sweeteners and the current research, et cetera. But of course, there's always more out there like stevia.

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Yeah.

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What are your thoughts? You know, it's just like the others in terms of, well, you talk about stevia in the other context.



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Yeah, yeah, no, no, that's a great question. So stevia, of course, it comes, it's a plant-based sweetener.

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There have not been, as it hasn't been around quite as long as the other ones, so there haven't been quite as many studies with it, however,...

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not that I am aware of. I don't know of any studies linking it to blood cancers.

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And of all of the sweeteners, it's probably one of the ones, you know,...

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you're always going to get mixed data, but consistently on stevia, I'm not seeing any red flags with it and so might be a good option.

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Let's hope there's no red flags about the next thing I'm going to ask about, specifically yogurt, live yogurt, you know,...

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it's various yogurts out there. Any counterindication with either any of the other things we're taking or with CLL itself?

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Having live bacteria in your body kind of thing. Could you take us through your thinking about yogurt?

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Yeah, this is a good question and, um, you know, you know I guess the caution of it comes from some rare reported cases of yogurt bacteria or probiotic supplementations causing people to actually have bacteremia or that bacteria growing in their blood, which is a really serious and life-threatening infection.

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Again, these cases are pretty rare and usually are in folks that are really severely immune compromised so, people who have just had a bone marrow transplant, people who have just had a solid organ transplant, people who are getting immune suppression for an autoimmune condition. You have to have...



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pretty severe immune suppression and you know some folks with CLL will fall into those categories.

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And so again, I would talk with your doctor to understand your individual risk.

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But on a general level, I think eating a few cups of yogurt every day that has the bacteria in it, I think is probably good for your bowels to have the good bacteria in there.

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Do you need probiotic supplementation? Again, some people swear by them that that's the only thing that makes their bowel movements regular and normal.

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And I would say, again, just make sure your doctor is aware that you're using them. For the most part, they're probably not going to be a problem.

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But just that that's that the thing that's in the background. If you're having some real severe immune suppression, I mean.

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We used to give people a lot of chemotherapy, FCR, fludarabine, cyclophosphamide, and rituximab. We don't give a lot of that anymore, but there may be patients on here that actually had that regimen and that really suppresses your immune system. And so, if you're following that treatment, I might...

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recommend against using probiotic supplementations or any additional yogurt. So again, it's kind of a case-to-case basis.

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I would say the risk is probably quite low. But if you have really bad immune suppression, again, bone marrow transplant, something like that,.

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it might be worth asking your doctor and always worth letting your doctor know you're taking them.

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Some, I think, related questions about other kinds of foods like kefir, kombucha, monk fruit sweetener. I know those are a little bit different situations, but could you talk about them? There has been some concern about monk fruit and some of the, there's something in monk fruit that may not be so great. What is your current view on those?

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You know, I'm going to be honest. I don't know a lot about the data behind monk fruit so I'm not going to comment on it directly. So, I don't want to quote anything incorrectly. But again, I have a general sense that, you know,...

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too much of anything can be bad in some way. You know, so, if you've done some sort of a diet where your whole diet is monk fruit, you know, I mean, of course, that's an extreme situation, but, you know, just...

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again, I think I had mentioned before, think about what you're eating every day. You know, like, for example, I love chai tea. And so, I generally am going to have one of those every day. And so, whenever I'm buying chai tea, I look at all the ingredients because that is something that I consume a lot of.

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And thinking, you know, is there anything there that I need to be concerned about because I'm doing a lot of this?

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You know, if you're like, I'm going to have a, you know, some monk fruit, you know, extract or whatever, you know, just every now and again, it's probably not as big of a deal.

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But if it's something that you're really consistently consuming, you really should be aware.

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What are the ingredients and products and what potential risks are there?

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Here's a question that there's 10 years of history on.

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You take a BTK like a ibrutinib, your fingernails start cracking, lots of other related skin issues.



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Yeah.

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The first answer was, well, stick your finger or fingernails in some oil or take biotin.

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After a decade of dealing with this, what is your recommendation for fingernails and skin issues in general?

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Yeah, that can be, um, variably severe. And, you know, speaking for someone who, you know, I lived in Utah for a long time, that is a very dry climate, I would say it's even worse there because the drier your skin is to start with...

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the more problems people have with this. I would say in general, nail recommendations, I recommend people keep their nails quite short...

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because they are going to break and be more fragile. You know, some people have luck with like painting with clear nail polish or, you know, just kind of providing a little coating on there.

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Again, I mean, cuticle oil can be helpful with those cracks that come at the end of the fingertips and are so painful.

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You know, one of, I mean, I grew up on a farm so we always used bag bomb...

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for those kind of things and I do think that that is helpful. Like, for example, if it is winter and those,, you know skin sores are cracking and bleeding, you know, you can put the, you know, put the bag bomb oil or the, the...

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solution on your hands and then put a pair of socks or a glove on before you go to bed.

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And then you have kind of this nice, moisturized hands when you wake up in the morning and that helps your hands to heal up a little bit.





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Keeping hydrated, I think, is really important as well. So, I mean, unfortunately, this is one side effect that there's not really a good magic cure for. It is just 10 years later figuring out how to, you know, to work around it and live with it.

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What was the name of that oil you just mentioned? Could you spell it?

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Bag bomb like utter bomb. So, like B-A-G B-A-L-M.

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Okay. Hey, thank you. I hadn't heard of it.

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Mm-hmm.

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One of the, in the preventive, prevent colds, we've talked about use of Emergen-C etc., there's some nasal sprays out there that are also supposed to protect from airborne germs.

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Any thoughts about those? Any experience with those and whether they may be helpful for CLL folks who are especially vulnerable?

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I don't have a lot of experience with those. I would say they're probably not harmful, again, but I'm not sure how helpful they are either.

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You know, good handwashing is probably way more effective than using them.

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Okay.

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Okay. There's, you know, thanks to the COVID situation, there's lots of new things for us to get injected with, Pemgarda, for example.

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How are you advising your patients? This is not exactly a supplement question, but how are you advising your patients about getting more COVID vaccines after they've already had COVID, whether they've already been vaccinated, getting Pemgarda as a preventive, et cetera, et cetera?

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What is your thoughts on those these days?

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Yeah. And I will say, you know, my thoughts on them have changed over time because I do think that for the most part, the variances of COVID are a little less virulent, meaning they're a little bit less likely to cause severe infection. Now that's not always true,...

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you know, especially depending on your immune system. And so, I do offer the COVID vaccines about every six months to people if they are interested in getting them. Of course,...

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you know, they do come along with some risks and some discomfort.

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The tests have shown with just one COVID vaccine probably doesn't create quite as much antibody response as a repeat or a booster vaccine will in folks with CLL, you can see a better effect with the boosters...

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and so that's something to consider. The Pemgarda, again, I will generally offer it to people, especially folks who have a lot of respiratory infections or maybe they have a job where they're just in contact with people all the time and maybe they're flying all the time for work or things like that, I will offer Pemgarda. This infusion is one hour. You can get it every three months.

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The company who made that, it's a little bit more advanced than other products that we've seen just because the company designed it in such a way so that they could modify the product to kind of mutate as the COVID virus...

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mutates. Again, none of these products are fully FDA approved and so take that with consideration. They also haven't been around for a long time...

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and so, you know, what are the long-term effects of them? We don't know.

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But in the short term, I do think injecting these antibodies, like Pemgarda, have been really helpful to keep people from getting COVID or have reduced the severity of infection when they do. I like Pemgarda because they specifically tested in folks who had immunocompromised conditions.

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And so, you know, I would say I discuss it. Is it a hard recommendation like everybody should get this? No, it's not. Again, it's kind of a risk-based. And if you're somebody who maybe you live on a farm, you don't have a lot of daily contact with people, things like that,...

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is it worth getting it? Probably not. But again, it's kind of a case-by-case basis.

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The safety profile, at least for short-term toxicity, looks really good. I have not, I mean, knock on wood, have not had people have reactions to Pemgarda,...

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things like that and so that, again, kind of case-by-case basis, but good thing to think about.

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You did not talk about sunscreens, skin cancer et cetera but it is an issue for CLL patients. And there have been several questions about it. Is there such a thing as the perfect sunscreen? Stick with mineral SPF 40 or whatever?

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What are your current recommendations on sunscreen? And please explain how important this is for CLL patients.

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Yeah, I mean, I think sunscreen or sun protection is so important for folks with CLL...

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and the reason why is because you are way more likely to get skin cancer. And it is related to sun exposure as well.

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A lot of clothing products have been really good about putting out products that they will actually list their rating of SPF protection.



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Because, you know, barrier protection like, you know, a lot of fishing shirts and swim shirts and things like that, they will have SPF right in them and those are really great.

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Wearing a wider brimmed hat and I just want to highlight wider brim because I see so many skin cancers on people's ears and their cheeks because baseball caps don't do anything to protect those areas usually.

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And so those are really good ways to protect yourself. Is there a perfect sunscreen? Probably not. But I think the best sunscreens out there that have the least amount of potential side effects are those mineral sunscreens, mineral based, you know, zinc.

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You know, there's some data about like the oxybenzone's and other things that is a little bit concerning and might have some disruption of, you know, your hormones or I think what, you know, what I choose and what I put on my child as well are the mineral based sunscreens. And they're not quite as comfortable, they don't rub in as well.

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But I still think it's the best thing out there. I had showed, one of the slides I showed was from a website, the Environmental Working Group, that Dirty Dozen slide. I got it off of that website...

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and I saw they actually do also have kind of a listing of sunscreens that they think are good products on there, which might be something if you're looking specific at, you want to find some specific sunscreen brand might be worth taking a look at that.

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But even if something in the title says mineral sunscreen, look at the ingredients because sometimes they work something else in there so it should just be, you know, zinc. It doesn't have to be the good old fashioned, like, you know, from the 80s the...

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like pink, the hot pink crayons that you rub on with the zinc but you know some of them rub in a little bit better than others.

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I still think they are the best levels. And something SPF 30 or higher and just make sure you're reapplying, especially if you're at the beach,...



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you know, especially in areas that include water because you're going to have sunlight reflecting off the water. So even if you have a hat on, there's sunlight coming from below too.

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And like skiing, you know, you're going to also have that reflection off of the snow. Just be sure that you're reapplying any of those exposed areas.

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With CLL who have the compromised immune system being out in the summer, being stung by a mosquito, a bee et cetera, what do you recommend? What's the topical approach? And should we really be proactive and go with some prophylactic stuff...

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to protect us from various things. And we can get into Lyme disease too, which must be real hard if you're on CLL. Could you talk about all that, please?

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Yeah. You know, some patients, you know who you are if you have it,...

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some patients with CLL get really significant reactions to insect bites.

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And, you know, to the point where you need to get steroids afterwards to soothe down the inflammation.

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You know, clothing is a good barrier. Looking at different types of insect repellent or you know using, um, you know citronella candles or things like that that can help to reduce the amount of mosquitoes in the environment...

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are good. You have to look at the, again, the ingredients for, um, the ingredients for those bug sprays. They have, you know, any bug spray is going to have a lot of different chemicals in them so just make sure you're looking at them.

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And do I have any specific ones that I recommend? No, I don't. There's a lot out there.

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But you know, wearing clothing to protect those areas that are most likely to get bitten helps a little bit. I mean, you know that some of those bugs can get underneath your clothes too.

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Um, but you know, there's no I would say 100% way to prevent it from happening.

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This should probably be the last question and thank you, Dr. Stephens, these have been great answers.

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A number of people are wondering about the measles situation, given the resurgence of measles.

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For someone who doesn't, you know, we can't have live vaccines, what do we do?

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I know. This is a great question...

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and one thing that I have been offering to my patients if they are curious or maybe, you know, for example, I have patients that work in the medical field and they're worried that they may be exposed to measles...

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you can check for titers to see how many antibodies you have in your system to measles.

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Because you might be surprised, you know, that vaccine you got in kindergarten or whenever you got it...

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you know, I know for me, because I work in the health field, I have to prove that I have titers to all of these things.

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And, you know, those vaccines, I still have a very good immunoglobulin levels to those. And so, a lot of folks with CLL just might actually already have intrinsically good protection from a vaccine that they got years ago...



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and it might feel reassuring to know that you do have that protection.

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Given the vaccine is not a good one to get, there's the theoretical concern by getting a live virus vaccine that you could actually get the virus.

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You know, how likely is that to happen? You know, back when we had a shingles vaccine, I would say I had tons of patients with CLL come to me. They didn't know that they had CLL and maybe they got the shingles vaccine, you know, just like...

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three months ago, you know, so I don't have exact numbers on how likely it is. But I would say, I don't recommend that people get the live vaccines. But everything is a risk benefit ratio...

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and if you're working in an area that's just overrun with measles, which I don't think anywhere in the US is that case right now,...

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you know, something to talk about with your doctor, whether, you know, doing a titer might be helpful to help you feel good one way or another about it.

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You mentioned titer a few times and it may be helpful to explain to folks that basically this is like an immunologist testing for your allergies and in a little needle kind of thing. Could you sort of explain how you find that out?

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Yeah, the titer for this one is actually a blood draw. And so, you basically just draw your blood and we test for how many antibodies and a specific antibody called IgG to the different, you know, to the measles or rubeola. You can also test for varicella.

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You know, you can test for most things that you had that there are vaccines for. You can test to see what your body's response was?

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By doing the blood draw.

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This has been great. We've covered an awful lot of ground.

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Dr. Stephens, could you give us some sort of summary or closing thoughts, so to speak, on the alternative medicine, integrative medicine, comprehensive wellness. It's got a lot of different labels.

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Yeah, no, and I will say that I really encourage people to take advantage of integrative medicine techniques. You may already have been doing it and you didn't even know. You know, I can't emphasize enough how important exercise is to general well-being...

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fatigue, all of these things. There's usually someone to help you out if you're having trouble getting started. For example, ask your doctor, you might be referred to physical therapy or physical medicine and rehab, dietary nutrition.

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There's support groups with the CLL Society. So, there's lots of people out there to help if you feel like you're having trouble getting started.

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I'll just loop back around. I mean, I mentioned Dr. Google. There's a lot out there. And so just make sure that you are really questioning the source of the information.

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And I never want people to break their banks on supplements...

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that haven't been proven or may actually have harmful effects. I will say I do not feel that complementary and alternative medicine has replaced any of our medications like acalabrutinib or zanubrutinib.

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And so, if you need treatment for your CLL, I use these as complementary therapies not in place of CLL specific directed therapy.

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And so just keep in mind there's lots of options out there. Make sure you're keeping in touch with your doctor, letting them know what supplements that you're taking...

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so they can work around with that. But I think there's a lot of things that can help people in general with their quality of life as a part of participating in complementary and alternative medicines.

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Really appreciate all that guidance.

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I also want to thank everybody who sent in their questions. There's a lot of great questions. Really appreciate it.

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As you can see, Genentech and other generous donors are helping support all this.

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I'd like to thank them personally on behalf of everyone for their support to help us.

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Thank you so much for inviting me today. It's been great and I really appreciate all your questions.

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As you can see.

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My pleasure. As you can see, here's the, thanks for everybody for attending. There's a survey at the end.

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That'd be great if you could provide some feedback so we can do an even better job next time.

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The event was recorded and the written transcript will be available on the website. So, if you miss something, etc...

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you can always catch it later. And again, if there's a question,...

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you can go to the Ask the Expert at [cllsociety.org](http://cllsociety.org). Just send an email.

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And don't forget, as you can see, there's another, our next event with Dr. Roeker and Jeff Folloder.

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I may have mispronounced his name. And of course, the CLL Society is investing in us, so maybe we should be investing in the long life of the CLL Society.

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Be strong. We're all in this together. And thank you all very, very much.