



## Podcast Transcript

### Living with Lyme Disease

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**Guest:** Cheryl Cuozzo, FNP-C, FAIHM, PLLC

Cheryl Cuozzo is a dual board-certified Adult and Family Nurse Practitioner, researcher, educator, author, and distinguished Fellow of the Academy of Integrative Health & Medicine (FAIHM). She is the first and only NP in Connecticut to earn FAIHM credentials. Cheryl is the founder of Cuozzo Health and Intentional Wellness. Cuozzo Health is her CT-based integrative medicine practice that specializes in Lyme disease and co-infections, Long COVID, and “undiagnosable” conditions that may stump mainstream medicine. Intentional Wellness is Cheryl's private, 1:1 health consulting and coaching program, helping motivated individuals across the U.S. lead active, fulfilling lifestyles while healing from Lyme disease or other tick-borne illnesses.

**Host:** Candace PIERCE: DNP, MSN, RN, CNE

Dr. Candace PIERCE is a nurse leader committed to ensuring nurses are well prepared and offered abundant opportunities and resources to enhance their skills acquisition and confidence at the bedside. With 15 years in nursing, she has worked at the bedside, in management, and in nursing education. She has demonstrated expertise and scholarship in innovation and design thinking in healthcare and education, and collaborative efforts within and outside of healthcare. Scholarship endeavors include funded grants, publications, and presentations. As a leader, Dr. PIERCE: strives to empower others to create and deploy ideas and embrace their professional roles as leaders, change agents, and problem solvers. In her position as the Sr. Course Development Manager for Elite, she works as a project engineer with subject matter experts to develop evidence-based best practices in continuing education for nurses and other healthcare professionals.

### Episode 1: Living with Lyme Disease

#### Transcript

Candace PIERCE: Hello, I'm Dr. Candace PIERCE with Elite Learning by Colibri Healthcare, and you are listening to our Elite Learning podcast where we share the most up-to-date education for healthcare professionals. Welcome to our podcast series, Living with Lyme Disease: Diagnosis, Treatment, and Healing. In this first episode, we're going to really dive into the complexities of diagnosing Lyme disease, which we know is a condition that often

presents with some really diverse and ambiguous symptoms. And then in episode two, we're really going to focus more on the treatment options and some strategies for supporting patients who are living with Lyme disease. Now joining me for this discussion is Cheryl Cuzzo. She is a dual board-certified adult and family nurse practitioner. She specializes in Lyme disease and co-infections, but also Cheryl, you have your own story with Lyme disease.

Cheryl Cuzzo: I do. Thank you so much for having me on, Candace. It's awesome to be here and speaking to this audience in particular. And my story started like everyone else's, pretty much. I was working within the allopathic healthcare system. So, I worked as a nurse and as an RN in a variety of different roles. And I even had a stint in pharmaceutical research as well as critical care and education. And yeah, so I've been like all across the spectrum, and after becoming a nurse practitioner, I spent most of my career in the acute and the subacute settings. But never ever did I expect that I was going to ever become a patient and that I would be a consumer of this healthcare system that I worked in for years. Not only that, but one who would end up falling through the cracks of the system. So, in 2014, I was hiking in Vermont, and I had an insect bite on my back. So, I didn't have an adherent tick. I just had a bite, a little bit of skin missing. I didn't really think anything of it. Two weeks later, I was acutely ill. I actually had flu-like symptoms. So, I thought I had the flu. And four days later, I was in the emergency room getting admitted for a seven-day hospitalization, which is a long time. Like you have to be pretty sick to be in the hospital for seven days. And I had symptoms that were affecting nearly every organ system in my body.

And despite the obvious tick bite or insect bite, I should say, the possibility of tick-borne infection was actually dismissed because I was told that my tests, which were the standardized CDC panel, had come back negative. So, they began treating my symptoms, but the cause remained a mystery. I was actually discharged with no diagnosis other than that I probably had an autoimmune disease and was told, you're probably going to be debilitated in 10 years to some level.

So, I inherently felt like there was something else going on. I was still curious about this bite on my back. And I went from provider to provider. I didn't get any clear answers. And despite having medical insurance, I actually spent \$10,000 that year alone out of pocket, trying to figure out what was wrong. I was just given medications to mask symptoms. Yeah, and I, nobody, nobody had answers. Nobody had answers. And I felt a bit medically gaslighted by certain clinicians as well, who absolutely told me absolutely with certainty I did not have Lyme disease.

So, I felt like my physical illness was also compounded by a lot of emotional and mental exhaustion by dealing with that and also dealing with. I had a lot of personal grief and loss that happened at the same time. So, I was completely depleted. But guided by my gut instinct, I ended up seeking out the care of a nationally respected naturopathic provider who was literally, like, practically in my backyard. And he eventually became my mentor. His name was Dr. Jim Sensenig. He passed away in 2019. But he was the one that, through specialized lab testing, diagnosed me with Lyme disease and co-infections.

And with this also, I had an active reactivation of the Epstein-Barr virus, having had mono as a kid. So, this was really the turning point for me. And I really went down the rabbit hole of embedding myself in research, functional medicine, and natural holistic remedies, everything I could possibly get my hands on because I wanted to do everything possible to heal. And I was actually very fascinated by the whole journey because this was new for me as a patient. I was used to being the provider. So, through that process, I was able to give my body what I needed foundationally to be able to have my therapies start to work.

I actually healed without taking a single drug. So, everything was natural remedies. Yeah, and quite uncommon, but it does happen, and we can do it. So, it was a very long non-linear journey. I had some relapses along the way. I learned how to deal with the stress as well that was making things worse. So, a few years later, I actually felt like I was in even better physical shape than I was before I had Lyme. And I celebrated this by hiking to the summit of Mount Kilimanjaro. So over 19,000 feet. Yeah. It was a really symbolic climb because it wasn't really just about the physical strength I had regained. It was really about the whole journey that I had had, you know, slow, intentional, but incredibly moving journey that propelled me to my next chapter.

PIERCE: And you're really describing those intricacies of Lyme disease and how you get that diagnosis. So, I'm really grateful that you're here to share your story and to also share from that provider perspective to really help other providers navigate those challenges that you went through, really to improve their own patient outcomes. And what I didn't realize as I was preparing for this series with you is that Lyme disease is not actually just a US problem. I really thought it was just more of a US problem with ticks, but it's actually reported in all 50 states and also more than 65 countries worldwide, including Canada, parts of Europe, Asia, and Africa. So, Lyme disease in itself is very far reaching.

CUOZZO: It is. Yeah, there's millions of people worldwide that are suffering with it. And you're correct. I actually looked up recent statistics, preparing for today. And the most recent are more than 80 countries. And it is in all 50 states. So of course, we have areas that are more, you know, more endemic than others like the northeast where I live. But it is in all 50 states.

PIERCE: Yeah. So, can you start with walking us through what is Lyme disease and the primary causes and vectors? Because I mean, we know tick, tick-borne illness, but are there other vectors besides ticks?

CUOZZO: Yes, so let me just start by explaining what Lyme disease is. So, Lyme disease, for those who don't know, is an infection that is caused by a spirochete bacterium, so a corkscrew-shaped bacterium, which is known as *Borrelia burgdorferi*. So, it's generally transmitted through the bite of an infected tick, most commonly what we call the deer tick or the black-legged tick. And just to give a little historical context, in the 1970s, there was this cluster of people in the area of Lyme, Connecticut, which is actually not far from where I live at all, who presented with symptoms very similar to juvenile rheumatoid arthritis. There were a lot of children that were also involved with this symptomatology.

And so, studies were being done to try to figure out what was going on. And a few years later, an entomologist by the name of Willie Burgdorfer discovered the bacterium as being the cause of these symptoms. So, it was subsequently named after him. So *Borrelia burgdorferi*, and it is most common in the northeastern, north-central, mid-Atlantic, and Pacific coast states, but like we said, it's been found in all 50 states. And ticks go through life stages and all life stages of ticks can transmit Lyme, but the little nymphs, which are like the size of a sesame seed, are the most likely culprits. So, yeah, a lot of people don't know that they even had a bite. And so, when a tick bites, it actually their saliva contains an anesthetic. So oftentimes the bites are painless. So, you don't know they're there, and it's teeny tiny. The longer it's attached, the higher the transmission risk. So, it's a really tough disease. And so, to your question, there is some evidence that suggests the presence of Lyme in other insects, mosquitoes and spiders. I personally, I think I may have had a spider bite by the way that my bite presented. It was a very strange-looking thing, but I can't be sure, and I never will know, but there is some evidence to suggest it is in other insects. And there's also evidence to suggest that there's a congenital transmission from mother to child. So, if the mother contracts Lyme in pregnancy, she could potentially pass it on to her child. There are some rare reports of possibly placental issues, miscarriage, and stillbirth related to that as well. And lastly, there is some research ongoing about a potential sexual contact, so person-to-person transmission via sexual contact as well. So, there's, yeah, yeah, yeah, there's a lot of discovery being had.

PIERCE: So yes, there is, and I never would have thought that either. So, I'm a little surprised that that is showing up. So, I do find that interesting. Now, what are the common early symptoms that you see for Lyme disease and how do those symptoms progress if they're left untreated? And I know you have your own nonlinear story of how your symptoms progressed, but also, you know, what is that typical?

CUOZZO: So, my story is an individual story. In a way, though, it does happen very typically to people that they're fine, and then they're not fine, and suddenly they're very sick. But then there are some people that it's more insidious. There are stages of Lyme. So, I always say to people, Lyme shows up differently in everybody. It is known as the great imitator. And that means that it can mimic other disease processes like multiple sclerosis, RA, ALS, and mood disorders. So, it does not follow a linear path for most people, but there is a three-stage progression that happens.

And stage one is early localized Lyme. So, this is like the first 30 days after a tick bite where the bacteria is multiplying near the bite site. And this is when people typically will present with flu-like symptoms like I did. Maybe not so acutely ill but will oftentimes have usually fatigue is one of the number one symptoms and fever, chills, headache, muscle and joint pain, swollen lymph nodes.

This is also where you might or might not see the classic bullseye rash, which is the erythema migrans rash. So actually, less than 50% of patients get this rash. So, we can't count on the fact that somebody will or will not have a rash. And it doesn't always actually appear as that bullseye or target-looking rash. My rash actually, you could almost not even

tell there was anything there, and I have a picture of it, and you can kind of see in the picture this hue, but it was very elusive. And also, the rash does not have to occur at the site of the bite either, to make it that much more complicated. So yeah. So, if you could catch it in stage one, it is a little bit easier to treat, but it's oftentimes not caught early enough, and we'll eventually talk about that.

Stage two is early disseminated Lyme. And this is weeks to months after infection. And so, the bacteria are now spread through the body. It forms a protective biofilm around itself, which makes it that much more difficult to penetrate and kill off the bacteria. So, symptoms start to get much more complex. You'll see sometimes people present with Bell's palsy, they'll start having severe migraines and neck stiffness, you know, like meningitis-type symptoms, shooting nerve pain and numbness. I had the worst nerve pain down my arms and legs, that I actually couldn't walk by the time I got to the ER, I couldn't even walk.

Patients will have migratory joint pain. You could have eye issues like uveitis or spatial visual processing issues. Cardiac symptoms are actually very common. Lyme carditis is common, and a lot of patients will get POTS, or what's called postural orthostatic tachycardia syndrome. So, it's a dysautonomia issue. And also, sometimes patients will develop a mast cell activation syndrome or MCAS. So, there's all these disease processes that can happen.

PIERCE: That makes me want to ask you, so if somebody comes to you with symptoms of POTS, you then maybe just go ahead and test for Lyme disease just to make sure that...

CUOZZO: Mm-hmm. Yes. So, I do a really, really comprehensive intake. So oftentimes, if somebody presented with POTS, I could kind of put some puzzle pieces together with other things that would make me suspicious of Lyme. And, you know, I'm also asking questions about exposure and things like that. But I would more often than not test if somebody comes in with a symptom like that. And like I said, they usually have other things going on as well. But the testing is a very complicated thing to deal with as well, because it's not always accurate. So I did want to mention too, that sorry, I did want to mention just before I keep going down the rabbit hole is that we're talking about *Borrelia*, Lyme *Borrelia*, but I just want the audience to also know that there are co-infections that happen, that other pathogens can exist and can be transmitted within a tick bite. And so, ticks carry a bunch of other pathogens that can make the symptoms much more severe and actually the treatments more complicated. So most chronic Lyme patients have at least one co-infection. They say that over 30% report two or more. I think it's way over 30%. I had a co-infection of mycoplasma. And just so the audience is aware, the most common ones that we see are *Babesia*, which is actually a parasite, *Babesia*, *Bartonella*, *Ehrlichia*, *Anaplasma*, *Rickettsia*, which is known as Rocky Mountain spotted fever, *Mycoplasma*, which is an atypical bacteria. And then there's tick-borne relapsing fever, which seems to be becoming more common. That's actually a relative, it's in the *Borrelia* species, but it's a relative to the Lyme *Borrelia*. And then there's also tick-borne viruses as well. So, these things will all complicate everything else that we're talking about and can become much more complex to diagnose and treat. And then there's stage three.

PIERCE: How do you differentiate what you're looking at?

CUOZZO: Yeah, it's hard. So not everybody goes through all three stages, too, you know, and some just go right into late-stage Lyme, which is stage three. So, it's tricky. There's no single standardized diagnostic criteria or treatment protocol. And so sometimes it becomes a diagnosis of exclusion. If you test somebody and you get a negative result, it can also really just be based on clinical picture, especially with no rash or no known tick bite. So, clinicians need to become really astute investigators. And there's some red flags that would alert me that if somebody has suddenly, you know, developed this intense fatigue, they have migratory joint pain, and a big one is actually cyclical symptoms. So, patients that will say every three or four weeks, things get worse for me. And actually, a lot of them will tell you that they feel worse around the phase of the full moon.

So, this is very common. I hear this all the time where they say when there's a full moon, I feel like garbage and then things seem to get better. So just being aware of those cyclical symptoms. Also with women, they can be cyclical around their menstrual cycle. So, asking also about not just have you had a tick bite, but have you had any insect bites, environmental exposures so mold is a common cofactor for Lyme as well. So those are things you also want to address. And then travel history also. You'll want to ask them if they've been out of the country. I actually, when I was diagnosed or when I got sick, about a month and a half, I think before that, I traveled to Iceland. So, they were asking me all kinds of questions like, were you like hiking through caves and did you eat unpasteurized cheese and all these things, which I had done none of. So yeah, it's really the clinician who needs to remember that testing is not the be-all end-all of excluding Lyme as a diagnosis.

PIERCE: So, what I hear you saying is that most of the diagnostic testing for Lyme disease is not that reliable.

CUOZZO: It is not.

PIERCE: So, what do you do?

CUOZZO: So, I will tell you what the CDC standardized testing tells you to do. The CDC standardized test says to measure the IgM antibodies. So that would tell us if there was a recent infection, and the IgG antibodies to see if there that would tell us if there was a later or persisting infection, to see if these come up positive. So, it's a two-tier testing. The first tier is a screening, it's the ELISA screening. If the ELISA is positive or equivocal, then the lab usually automatically does the Western blot, but it won't run it if the ELISA test is negative.

And then the Western blot detects antibodies to multiple *Borrelia* proteins. So, for the CDC to say that a test is a positive result, you either have to have two out of three positive IgM bands, or five out of ten at least five out of ten positive IgG bands. And there are certain bands that are more specific to Lyme. The limitation of this though is that the ELISA test, which is the screening, is false negative at least 50% of the time. So, the CDC criteria are missing at least 50% of actual cases. I had a positive ELISA and on the Western blot, I had

only two positive bands of IgG bands. So, they said my test was negative. Now as a clinician with somebody who is that sick, knowing now what I know because I didn't know it then I absolutely would have treated this person. So yeah. And so, there's actually some states that require the labs to disclose on the lab report that a negative test does not necessarily mean that there's a lack of infection.

So, providers are starting they're understanding this and there are specialty labs. There are quite a few specialty lab tests that you can send out. IGeneX is a very well-known one. Vibrant Wellness and MDL are probably the three most well-known. So, they have a broader coverage of the strains, and they include more bands than the CDC criteria does. So, but it's costly, it's not always covered by insurance. So, there's barriers to access there. But the clinical diagnosis is key. You cannot just go by the labs alone.

PIERCE: Does the timing of the test impact the accuracy of the test?

CUOZZO: It does. And so that's where we run into a lot of false negatives, because if it's too early and you haven't mounted the antibodies, the test is going to be negative. And also, some patients, they don't present so acutely ill that they're not really sure what's going on. And then they wait to be tested. So, it's like a really narrow window of opportunity to get a positive test. Those tests the CDC test was really meant just for surveillance purposes. It wasn't really meant to be this diagnostic tool that we were going to base everything off of. So again, that's where we can't really rely on the tests. We really need to go by the whole clinical picture.

PIERCE: Even as a surveillance tool, it's still missing 50% of those that they would need to know had Lyme disease. So, they're not really surveying well.

CUOZZO: Yeah, I mean, it's a 50-year-old no, they are not. And it's a 50-year-old test. I mean, it's just crazy.

PIERCE: It really is, and that makes me wonder, how do you in the beginning when you start seeing somebody how do you differentiate Lyme disease from any of the other conditions that might have similar symptoms?

CUOZZO: So, it's really that clinical suspicion and considering the regional risks of infection and again, listening to the patient and also their lived experience. You really want to get a whole timeline of what's been happening. When did it start? What were the first symptoms? How did it progress? Is it cyclical?

What other are there environmental factors involved? And then of course, also considering co-infections adds in a whole other level. If I have if I feel that I need to test, I will sometimes use the CDC version of the test because most of the time their insurance will cover it. I've actually not had a patient that it didn't. And if it came up positive with any positive bands and they're presenting clinically like somebody who has Lyme, they should be receiving some sort of treatment. So sometimes that is a good starting point because you might get

the IgG positive bands. If I don't if I get a negative test, we could consider doing one of the more specialized tests or ask if there is something else going on that we need to investigate? So, it does oftentimes it does become a diagnosis of exclusion for a lot of people, unfortunately. But by then, now you're talking stage three, late disseminated Lyme. And now things tend to be much more difficult to treat.

PIERCE: Right, you're checking a box of rulings. What can I cross off of my list that leaves me with Lyme disease, which some of the things you've mentioned I identify as challenges for healthcare professionals, like we don't have a reliable diagnostic tool. Lyme disease mimics so many other diseases that we have and syndromes that we have out there, plus you have comorbidity infections. So besides those, what other challenges do you have as a provider trying to diagnose Lyme disease, and how do you overcome those? Are there others?

CUOZZO: I would say the lack of consistent guidelines around diagnosis and treatment makes things difficult, especially when you have to liaise with other healthcare practitioners that maybe aren't quite so open to thinking out of the box. So that can make things a bit difficult. So, you do want to get your network of people that you know are going to be a little more open-minded about talking about something that's not showing up on a test as positive. There's a stigma around the term chronic Lyme, because the CDC actually doesn't recognize Lyme as a chronic infection. And I actually I went to a Lyme specialist that was actually working in the same network that I was working in at the time, and he said to me, you do not have Lyme disease. There is no such thing as chronic Lyme. You have something else going on. So, you need to find your people and stick with them. Yeah. And the CDC will now say that people have, like, a post-treatment Lyme syndrome. That it's, you know, just like not a chronic infection. It's a result of like damaged tissues and things like that, but that it's not a chronic infection per se. So at least we're moving in a little bit of a better direction, but there are a lot of challenges as a healthcare provider with Lyme for sure.

PIERCE: Would you say that Lyme disease in general has a stigma attached to it, and what that stigma might be?

CUOZZO: For patients, I think the diagnosis of Lyme has a stigma when it can't be proven on a piece of paper. Because patients have a hard time making people understand that they are actually sick. So, what they encounter a lot of times is, well, you look fine. And if you have Lyme disease, why don't you just take an antibiotic and be done with it? I could not tell you how many times somebody said that to me when I said, it turns out I have Lyme disease. And they're like, but yeah, you look okay. So, can't you just take an antibiotic? So, there is a stigma, I think, attached to it. And it's hard because they're spending a lot of money. So, they're financially burdened by their disease. They may not be able to work. I mean, I had to take three months off from my job when I was sick. And I was getting urged to come back and work. And I actually wasn't even cleared to go back by any physician. So, there is a stigma for sure. You know, you look okay, but you don't feel okay.

PIERCE: That invisible illness. Yes. All right, as we close out this first episode, I know I do now, and I hope you know our listeners do as well have just a better understanding of the



complexities that's involved in diagnosing Lyme disease and just Lyme disease in general. And that accurate diagnosis is crucial for effective treatment and patient care and really working to rule out anything else that it could be so that they can get the appropriate care. So, I hope you will stay tuned for our next episode where Cheryl will be back to explore treatment options and strategies for supporting patients on this healing journey with Lyme.

## Episode 2: Living with Lyme Disease

### Transcript

Candace PIERCE: Hello and welcome back to our series, *Living with Lyme Disease: Diagnosis, Treatment, and Healing*. Cheryl Cuzzo is a board-certified adult and family nurse practitioner who specializes in Lyme disease and co-infections, and she is back with us. If you missed our first episode, make sure you check it out. We really got into the complexities of what it looks like diagnosing Lyme disease. So now in this episode, we are going to focus on treatment options and some strategies for how you can support patients who are healing from Lyme disease. Now Cheryl, before we jump in, I was looking at some of the data from the Centers for Disease Control and Prevention. And this was from 2023, but it stated over 89,000 cases of Lyme disease were reported to the CDC by state health departments and the District of Columbia. But there was another number that was much bigger than the actual cases reported, and it was that approximately 476,000 people may be diagnosed and treated for Lyme disease each year in the US. And I saw you shaking your head when I started to say the bigger numbers. So, what are your thoughts on this? Because I know it included what you talked about in the first episode, was that clinical suspicion that, you know, they do actually have Lyme disease, even though it says that they don't have Lyme disease. So, what are your thoughts on this data?

CUOZZO: So, the data that's frightening, right? Those numbers are frightening. And what's even more frightening is that I would venture to say the numbers are probably even higher than that, based on like things that we talked about in the first episode with how difficult it is to diagnose it. And, you know, aside from the fact that there's that many cases reported, there's even like, there's that many people that are also still symptomatic, still not well. So, it's because it's so hard to treat. So, it's a staggering number of people that are getting sick. And it's a staggering number of people that are staying sick as well. And like I said, with the way that the testing is and that failure rates to come up with a positive screening, we're missing a lot of cases that could be reported.

PIERCE: Now, what is the standard treatment protocol that we have for Lyme disease, and does it vary based on the stages you walked us through in episode one?

CUOZZO: So, there is variability, and the trouble is that there's no universal effective treatment for Lyme. So, the diagnosis makes it hard to manage, and the fact that there's the lack of treatment protocol makes it hard to manage as well. So just to give you a little bit of background, there's this really deep division within the medical community as to how these patients should be treated. And some of it does vary by stage depending on which one

you're following. So, there's two main schools of thought that guide Lyme treatment. There is the CDC, and that is actually they support the Infectious Disease Society of America.

And then the International Lyme and Associated Diseases Society, also known as ILADS. So, the CDC's approach is much more conservative than ILADS. The CDC considers Lyme to be relatively easy to treat, recommending shorter courses of antibiotics in early stages so even like just 10 to 21 days of a single antibiotic. Longer courses or more or IV route are more recommended for later stage, and that would be oftentimes up to like a 28-day course. And the CDC does actually admit that there are people that have symptoms six months or longer after treatment, but they won't call it chronic Lyme disease, since they don't want to insinuate that it's still an infectious process. So, they call it post-treatment Lyme disease syndrome. They estimate that about 10% of patients go through this. But there's other research there was some research in the *New England Journal of Medicine*, and I believe Johns Hopkins has some research that said it may be closer to 20% or even as high as 45% of these patients that are treated. So, for some reason, mainstream medicine has just been very resistant to honoring the term chronic Lyme. But ILADS, on the other hand, takes a much broader view. So ILADS will incorporate, like we talked about in episode one, the clinical presentation of the patient, their symptom profile, and then those co-infections that I mentioned, which makes everything just that much more complicated. So, they take all of that into their treatment decision. And the testing really becomes more of a supportive diagnostic tool that sometimes it's just a nice to know and nice to have, but it doesn't always maybe change what you're actually going to do based on the clinical presentation of the patient. So, their treatment protocols are much more individualized and for far longer duration. So, it also makes a difference how long the patient has been ill for, because their bacterial load is that much higher. That's the two schools of thought around the treatment.

PIERCE: If you're treating for Lyme disease, and I'm assuming you can do studies or tests to determine if they have these co-infections that we talked about in episode one. And if you determine that they have one of these known co-infections, would you go ahead even though everything else has shown negative for Lyme disease and also test and also treat them for Lyme disease plus the co-morbidity?

CUOZZO: Yes, yep. So that is something to consider is that there's other possibilities other than Lyme. It's just usually you see the two, or you see the Lyme and then the co-infections together. So, the answer is yes, you would treat for both. And there are some very specific treatment protocols for the specific co-infections as well, but you would want to most likely just combine the treatments and cover Lyme as well as the co-infections.

PIERCE: And what type of treatments are you doing? I know we've mentioned antibiotics. So, antibiotics are something that you do depending on what stage that they're in plus anything else that is pulled into that treatment?

CUOZZO: Yes, and just for the general knowledge of the audience, the general classes of antibiotics used are typically tetracyclines so many people know doxycycline is kind of a go-to when it can be used penicillin, cephalosporins, macrolides, and then also you can use the

anti-mycobacterials like rifampin. So, these would the treatment strategies vary by stage as to how long you might treat somebody. And antibiotics are the cornerstone for acute Lyme, but in chronic cases, they're not usually enough. So, we do need to take more of an integrative approach and care, providing the body with what it needs. That's where integrative medicine really comes into play and shines. So, we use a lot of complementary therapies, sometimes in conjunction with the antibiotics. But in my case, I actually didn't even take antibiotics I did everything with very strong herbals and other complementary therapies. So, some of the herbal remedies that we use that have antimicrobial and immune system support are things like Japanese knotweed, sweet wormwood, myrrh is a really big one. We use Andrographis, echinacea, cat's claw. A lot of these are also anti-inflammatory as well. Then you would consider adding other things like turmeric or Boswellia. So Boswellia is frankincense, and they are anti-inflammatory and they're really great for symptom relief. And then homeopathic remedies are an awesome way to support healing. I did really well with homeopathic remedies when I had Lyme to help calm the symptoms that I was having. So, I used one called Rhus tox for the Lyme arthritis that I had and Ledum for the skin rashes, Arsenicum (album) for chronic fatigue. I mean, we could go on and on the lists are very, very long as to what we can use that would benefit these patients.

PIERCE: Now I know we're talking about antibiotics being the cornerstone of treatment for Lyme disease, but you know, long-term use of antibiotics comes with some potential for side effects. So how do you how do you get around those? How do you help the patient through those side effects of long-term use? Because this is kind of a longer-term use of antibiotics, regardless of what stage they're in.

CUOZZO: Yeah, it is. And we know that when you take an antibiotic, it's basically dropping an atomic bomb into the body every time you take a dose. We want to be preparing the body for that and mitigating the effects that can often lead to that gut dysbiosis and yeast overgrowth and immune suppression. So integratively, we try to, I like to prepare people ahead of time to kind of open up those detoxification pathways and get everything moving to support the elimination of the toxins once the bacteria are dying off but also supporting the gut health and immune function and reducing the inflammation. So, lifestyle, actually lifestyle foundations are critical here. In my practice, I developed what I call my five healing foundations, which involve nutrition, movement, managing sleep, managing stress and mindset, and then clean living. So, removing toxins out of your environment as best as you can.

So, I like to try to stick with whole food, nutrient-dense diets with whole food supplemental support. And then talking to the patient about how can we get you to be moving your body so that your lymph, your lymphatic system is moving and you're draining you know, these detox pathways are draining appropriately but without overtaxing the patient. And then adequate or restful sleep most of these patients are not sleeping well. So, I'm trying to figure that piece out. And a lot of them have adrenal issues, adrenal fatigue, and all that goes along with being ill. So, the sleep is paramount. Obviously, if you're not sleeping, nothing is going to work well. And then how to manage stress, and then, like I said, clean living and removing

as many toxins as you can from personal products and household cleaners and replacing them with more natural things.

And then also as side effects of not only the antibiotics, but even the herbal antimicrobials it's really important to know that when you're going to be treating a Lyme patient, that many of them develop a side effect of these antimicrobials. When they start to have a die-off of the bacteria, it's called the Jarisch-Herxheimer reaction. It is colloquially called Herxing. And this phenomenon happens during treatment when the bacteria is starting to die off. It's releasing toxins faster into the body sometimes than the body can eliminate them. So oftentimes patients experience this exaggerated, intense version of the symptoms they were already having or new symptoms as well. So, they usually feel worse before they feel better. Sometimes we're like, well, that's a good thing, but it's still they don't feel well. And it can happen like days to weeks into treatment.

So, length of herxing tends to vary on the bacterial load and co-infections and things like that and whether they're detoxing well enough and whether their liver was supported well enough. So, I like to do that preparation first if they're not already on treatment, so that when we're killing off pathogens, it's not the most unpleasant experience they've ever had. So, there is a pattern or a protocol to it.

PIERCE: It seems like when you hit that mark for the patient, that if they are not well educated on what's happening, that that's the point where they're like, this is making me worse. I'm not going to take this medication anymore versus understanding, no, no, no, no, it's working. We just got to get through this phase.

CUOZZO: Yeah, and there are things you can do if it does happen. Despite prepping the body as best as you can, it oftentimes still happens. And so, it is disconcerting, and they do feel like, well, this is making me worse, I'm going to stop taking it. So, you want to prepare the patient that this is a distinct possibility that they may have this happen. And to let the provider know not just live through it and not inform your provider. Because I tell people, we're working as a team. I want to know what's going on. And a lot of them don't want to contact you because of experiences they had with other providers before. So, if you're somebody who's going to be treating Lyme patients, you need to keep that door open and check in with them because you want them to stay the course. And you also want to know if something's not working right for them as well. So yeah, but it's very disconcerting. When I was herxing, I was like, okay, I don't know if I want to do this. But I stuck it out and I yeah, yeah, I did some things that made it better.

PIERCE: I don't want to give up. Now you mentioned some homeopathic therapies that you did. You talked really well about the herbal supplements and what they were, what they did to help you, but what about things like acupuncture?

CUOZZO: Yeah, so gosh, there's so many integrative modalities that we can use. And I personally used them, and acupuncture is one of them. I still go for acupuncture regularly. But I used acupuncture I think I went for a period of time, like three times a week. And it is

wonderful for relieving pain, inflammation. It helps get your nervous system into balance. They can work with you to relieve the congestion in the liver to help relieve the possibility of herxing. Just get everything moving. And I mean, I can't say enough about it. So that is something I recommend to my patients is to get into an acupuncturist and have that regularly.

And then also manual lymphatic drainage. So, there's massage therapists that are certified in MLD or manual lymphatic drainage. So, this is another really good modality to get the lymph system moving. Chiropractic, I did Reiki also to help with energy balancing, and I always felt much better after I did Reiki. And mind-body practices, meditation, deep breathing, all of these things significantly improve the quality of life while you're going through that healing process. Unfortunately, these things typically are not covered by insurance and they cost money out of pocket. But for me, I think it propelled my healing so much faster and in a less painful way. It was absolutely worth it.

PIERCE: One of the things, as you're talking about all of these herbal supplements, all of these homeopathic remedies and antibiotics. This seems like it's going to take a lot of time out of the patient's life every day, every week, to try to heal and get better. So how do you help your patient understand the time that it's going to take that needs to be committed to healing from this?

CUOZZO: It's a learning curve for a lot of people, because we're used to just taking a medication and hopefully it's working and kind of going on our merry way. But a lot of these patients have gone through this journey for a while now. Lyme patients are very, very well educated. They do a lot of research. So, they most of the time already know that this is going to be a nonlinear, long journey for them, and they're prepared to do the work because they so desperately want to get back to the life they had before they had Lyme.

So, but it does require, again, that we team up with them because it's very taxing. It's taxing mentally. It's taxing emotionally. So, I usually recommend that patients seek either some kind of therapy or seek out a group that they can relate to. So social media is great for that because there are just tons of Lyme groups. There's even like subgroups for people that...

were diagnosed with ALS and it was Lyme, were diagnosed with MS and it was Lyme. It goes on and on. So, a lot of them reach out to those groups as well and they, yeah, I mean, it's hundreds of thousands of people. And imagine being told you have ALS and it's Lyme disease. Yeah. And there's a lot of PTSD involved too. Mm-hmm. Mm-hmm.

PIERCE: The heartbreak of the house I mean, relief that it's not ALS? Yes, and trust issues. You have the relief that it's not ALS, but then you have to understand Lyme disease, which in and of itself is also really hard. And then just that is hard. I can't imagine. Emotional whiplash.

CUOZZO: Yes, that's a wonderful term for it. Absolutely. And so we as clinicians need to know that we need to be screening them for depression and anxiety that surrounds that kind of trauma and the trauma from chronic illness, and empowering them with even the

small wins, you know, just reminding them that every little win is taking you to, you know, over the hill. Empowering them, because I just remember that I felt very powerless in a system that I had worked in for years. You know, I was able to navigate the system, and I felt like I just had lost all my power, and I wasn't believed. And so, we need to make sure that we're empowering them and we're including them in their treatment regimen as well you know, give them a say.

PIERCE: Now you've talked about the post-symptoms, post-treatment symptoms. And I saw I think this was a CDC statistic and it said up to 34% of Lyme patients experience symptoms of post-treatment, often referred to as persistent Lyme disease. So, I mean, I would think that that would highlight the need for ongoing management and support, and yet we don't use the term chronic Lyme, or we don't recommend further treatment. But yet it seems like you need more treatment. You need more management and support. So, what do you do with that?

CUOZZO: It is possible for like, for myself, I believe that there's probably still Lyme in my body, regardless of the fact that I have quote-unquote, healed. So, whether I healed with Lyme in my body or whether I healed from it, I always have this belief that I need to do all the things that I need to do to keep my immune system at its utmost health so that I stay above it. And that goes for Epstein-Barr and parvovirus all the other things that can kind of live in the body. So, while somebody's being treated, and then that period of time afterwards especially if they're still symptomatic this is where the lifestyle modifications are paramount. And it needs to become a total lifestyle change. The mentality needs to shift to I need to do these things. I need to maintain this healthier lifestyle with these five foundations of healing for the rest of my life because that's what's going to make you healthy. That's what's going to make you well. And you're not most likely, hopefully you're not going to be on all the herbals and all the other stuff forever, but you will need to be dialing in your nutrition and moving your body and moving your body more as you start to feel better. And then listening to your body and not pushing it too hard and dialing in sleep and managing the stress and the things that you can control in your environment that are maybe more toxic, try to remove. So, it's really a long-term management of a lot of health coaching that happens to keep patients continuing to get better and to keep them in a healthy space so that they don't relapse. And like I said, even with the viruses that stick around forever, you know. Yeah, it's tough. It's tough, but when you're doing it consistently, it just becomes a way of life. And then you enjoy it, and you enjoy how you're feeling, and you want to keep it up. And then you become a good example for other people.

PIERCE: Yes, and that's a really good point is realizing how well you feel when you have made those lifestyle changes and realizing just how good they were for you. Now, as we as we, you know, kind of talked about some of the things that are lacking in the treatment protocols and the understanding in the diagnostic testing for Lyme disease are there any advancements, anything on the horizon, ongoing research really in Lyme disease treatment and management?

CUOZZO: There's a lot of research going on. It is a rapidly evolving field, but funding is always an issue with funding limitations. And, you know, these when new things do come out, they are very, very expensive. So that's something that needs to be worked out as well. But there are some promising developments. Like, I know there's some evidence there's some studies on stem cell therapy, and the early evidence is suggesting that it actually might help regenerate damaged tissues in the body. There's new antimicrobials and herbals, and there's people using DAPSONE therapy, methylene blue is a big one now that people are starting to use, and it's being studied more. There are clinical trials and, you know, the work's being done but there's a lot more work that needs to be done. So hopefully. There's a lot of people with Lyme, so hopefully it just the exposure becomes it becomes more evident that we need to focus on advancements and treatments.

PIERCE: Right, increasing the funding to these areas where so many people are affected so that they can get appropriate treatment. Absolutely. Well, we are coming to the end of our time for this series. So, is there anything that maybe you want to reiterate or maybe that we just didn't have time to touch on that you want to make sure our listeners know?

CUOZZO: I think I just want to wrap it up by reminding people that Lyme disease is not a one-size-fits-all condition at all. From diagnosis to treatment, it's complex. It's very individualized. And as providers, we need to keep an open mind about this and look outside the box and stay informed and be integrative in our approach because there's a lot more than just antibiotics that can help these people. And we've proven that time and time again. And so, I'm hoping that the integrative and the natural medicine spaces start to grow more, because there's a lot more, we could do to help patients.

PIERCE: Absolutely, and I see this as a need for, like, all areas of healthcare. We need to grow that area because there are so many things we can do that don't just involve medications and really do lead to living a more healthy life. There are lifestyle modifications. So, it's a really great callout. Thank you. Cheryl, it was so great to meet you. It was so great to have this discussion with you. I learned a lot about Lyme disease that I had no idea. I always knew that it was a hard disease to treat, but just how to diagnose it, the fact that there's no real standard protocols, that it's not one-size-fits-all there's so much that I learned from you today. So, thank you for being with us.

CUOZZO: Well, thank you for having me. I had a great time.

PIERCE: Yes, and to our listeners, thank you for taking time to listen to this discussion. If you found this information valuable, we'd love for you to share it with your colleagues. And I really encourage you to explore many of the courses that we have available on [EliteLearning.com](https://www.elitelearning.com) to help you continue to grow in your careers and earn CEs.