


AN EXPERT'S GUIDE ON NAVIGATING LYME DISEASE



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Free Ebook

Chapter 1

Video introduction to Lyme disease

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About the author



Dr. Daniel Cameron is a nationally renowned expert in diagnosing and treating Lyme and tick-borne diseases. He practices Internal Medicine in Mt. Kisco, New York—where he has helped patients for over 35 years. He’s on a mission to ensure other health professionals and their patients navigate the diagnosis and treatment of Lyme disease.

Dr. Cameron holds a medical degree and masters degree in epidemiology from the University of Minnesota and completed residencies at Beth Israel Medical Center and Mt. Sinai Hospital in New York. He served two terms as president of the International Lyme and Associated Diseases Society (ILADS) and as lead author for their two evidence-based treatment guidelines.

1st Video - Introduction to Lyme



The following four brief videos are an ideal start for anyone newly diagnosed with Lyme disease or a tick-borne co-infection. A transcript follows each video. A patient’s family and friends may also find these videos helpful.

[Here is the first video](#)

Transcript for Lyme Disease 101 video

Lyme disease is not new, it's been around for over 5,000 years and infects about 300,000 people per year in the U.S. alone. In 1977 three Connecticut communities reported an epidemic of oligoarticular arthritis. Several years later in 1982, Dr. Burgdorfer discovered there was a spirochete bacteria in the tick, which was named after him — *Borrelia burgdorferi*.

The spirochete can be transmitted through the bite of an infected black-legged tick. The longer a tick is attached the greater the chances are of it transmitting a disease. As the tick feeds on the blood of its host it releases the *Borrelia burgdorferi* bacteria, as well as other co-infections, into the bloodstream. Anyone can become infected with Lyme disease.

The highest number of reported cases in the US occurs among children 5 to 14 years old and adults 45 to 54 years old. According to the Centers for Disease Control, the majority of cases occur in the Northeast and Upper Midwest. But cases of Lyme disease have been reported in all 50 states.

Identifying Lyme disease is not so easy for a number of reasons. Laboratory tests are often unreliable and the number of infectious diseases carried by ticks has grown significantly. Also, hallmark signs of Lyme disease aren't always present and many of the symptoms vary greatly from patient to patient and are similar to other medical conditions. There have been many cases where patients with Lyme disease have been incorrectly diagnosed with multiple sclerosis, thyroid disease, psychiatric disorders, fibromyalgia, chronic fatigue syndrome, autoimmune diseases: including lupus, rheumatoid arthritis and polymyalgia rheumatica among others.

The CDC recommends wearing light-colored clothing because it is easier to spot ticks, wear long sleeve t-shirts and pants, wear socks and enclosed shoes, remain on trails and avoid hiking through tall vegetation, apply repellents containing 20% or more DEET.

If you have pets, protect them with tick repellents to reduce chances of ticks being brought indoors. Another step you can take is to perform tick checks after you come in from outdoors. You can check for ticks a second time the following day since ticks will become larger from feeding and easier to spot.

Ticks prefer warm moist areas such as behind the knees, groin, belly button, underarms, behind the ears and hairline, so be sure to check those areas. Shower after being outdoors to wash off loose ticks but remember deer ticks can be submerged in water for 2 to 3 days and remain alive. Water will not rinse off or kill attached ticks. Check your clothing carefully and before you wash your clothes place them in the dryer at high heat. A recent study found that it only takes 6 minutes of high heat to effectively kill ticks in the dryer (Nelson et al. 2016).

The CDC recommends treating your clothing and gear with products containing 0.5% Permethrin. Permethrin should be applied in a ventilated area and will remain protective through several washings. Despite these recommendations it is still possible to contract Lyme disease or other tick-borne illnesses.

Remember Lyme disease is a far greater threat than is generally recognized, so even if you don't have Lyme disease be alert and informed.

2nd video - Lyme disease symptoms & manifestations



This second brief video is perfect for anyone seeking to understand the symptoms and manifestations of Lyme disease.

[Here is the second video.](#)

Transcript for symptoms and manifestations

Symptoms of Lyme disease can vary from person to person in their intensity, diversity and longevity. Some patients present an erythema migrans or bulls-eye rash. The bacterium can also cause atypical rashes. A rash due to Lyme disease is often not itchy or painful and usually appears between 3 to 30 days after the tick bite. It can fade and reappear and is often confused with a spider bite. The rash can appear anywhere on the body not just at the site of the bite.

Some patients may present with Bell's Palsy, Synovitis of the knee, hips and shoulders and Sacroilitis. When initially infected by a tick, patients may experience flu-like symptoms; however, since the Lyme spirochete are very good at avoiding the immune system, it can remain dormant for days, months or even years. Neurological and cardiac symptoms such as meningitis, encephalitis and carditis can occur but, more often symptoms can include, severe unrelenting fatigue and

joint pain, with or without swelling, sore muscles, neck and back pain, headaches, light, sound and temperature sensitivity, sleep disturbance, night sweats, irritability, anxiety, despair, sadness, lightheadedness, crying, poor memory and concentration, stiff neck, numbness and tingling sensations. The symptoms can worsen and fluctuate if the disease becomes chronic.

The full range of symptoms needed to recognize the disease may not be apparent to a physician during a routine examination. Some patients experience long-term consequences of Lyme disease. Types of chronic manifestations include Lyme encephalopathy, neurocognitive complications, post Lyme disease, neuropsychiatric Lyme disease, post Lyme disease syndrome, sensory neuropathy and carditis. Additional manifestations of Lyme disease include POTS. POTS is an autonomic dysfunction that can appear years after antibiotic treatment for Lyme disease, resulting in fatigue, cognitive impairment and orthostatic intolerance such as palpitations, lightheadedness, chest discomfort, shortness of breath, among others.

In a study from Tufts University School of Medicine, 24 of 27 Lyme disease patients presented with a mild encephalopathy which affects neurocognitive abilities. The mild encephalopathy began one month to 14 years after the onset of the disease and was characterized by: memory loss, mood changes and sleep disturbances. Other symptoms also included fatigue, headaches, depression, irritability and difficulty finding words. Another study found that 14% of 86 children who had Lyme disease exhibited neurocognitive complications such as: behavioral changes, forgetfulness, declining school performance, headache or fatigue and in 2 cases a partial complex seizures disorder (Tager et al. 2001).

Patients treated at the time of a bulls-eye rash may still feel sick and may exhibit manifestations of Lyme disease long after the initial tick bite. Diagnosing Lyme disease can be extremely complicated and treating it is also very difficult. Remember keeping yourself and your physician informed and engaged helps the process of battling Lyme disease.

3rd video - Understanding co-infections



This third brief video educates patients and their support system on co-infections.

[Here is the third video.](#)

Transcript for Lyme disease co-infections

Ticks often harbor multiple infectious organisms resulting in co-infections. Co-infections can be challenging to diagnose as symptoms frequently overlap with many of the other tick-borne diseases including Lyme disease. Physicians have found that co-infections can worsen Lyme disease symptoms as they are severe, persistent and resistant to antibiotic therapy.

Babesia is a parasite with over 100 known species and the severity of the Babesiosis infections vary greatly from patient to patient. Most cases of the Babesia co-infection involve *Babesia microti* and *Babesia duncani*. Babesia can be transmitted by tick bites or through contaminated blood transfusions. Symptoms of Babesia can include irregular fevers, chills, sweats, lethargy, headaches, nausea, body aches and fatigue, in some cases patients complain of shortness of breath. Babesia can be effectively treated with a combination of anti-malaria medications and antibiotics such as atovaquone with azithromycin.

Ehrlichiosis is a tick-borne bacteria that infects white blood cells. The infection is caused by *Ehrlichia chaffeensis* and *Ehrlichia chagrins*. Symptoms may include, fatigue, fevers, headaches and muscle aches. It can be treated with antibiotics such as doxycycline or minocycline and Rifampin. If left untreated, Ehrlichiosis can become severe and require hospitalization.

Anaplasmosis is a tick-borne infection caused by the bacterium *Anaplasma Phagocytophilum* and is similar to *Ehrlichia*. Symptoms may include, headaches, fever, chills, malaise and muscle aches. Anaplasmosis can be treated with antibiotics such as doxycycline or minocycline and Rifampin. This disease can be difficult to distinguish from Ehrlichiosis, Lyme disease and other tick-borne illnesses.

Various *Bartonella* species have been found in black-legged ticks in northern New Jersey and in western black-legged ticks in California. Research can be confusing because *Bartonella* can also be contracted through a cat scratch. Some patients had a streak mark rash and early symptoms usually

include fever, fatigue, headaches and swollen glands. *Bartonella* can be treated with antibiotics such as doxycycline and minocycline, azithromycin, trimethoprim and sulfamethoxazole, clarithromycin and rifampin.

Southern Tick Associated Rash Illness, or STARI, is an emerging tick-borne illness related to Lyme disease and was identified in the southeastern and south-central United States. STARI is believed to be transmitted by the Lone Star tick; however, it is not officially confirmed as of yet. The hallmark sign of STARI is an EM-like rash similar to that in Lyme disease. Patients may also experience fevers, headaches, stiff neck, joint pain and fatigue. The long term consequences and treatment of the illness have not been established.

Borrelia miyamotoi is a spiral-shaped bacteria that causes tick-borne relapsing fevers. The development of a rash is uncommon with *Borrelia miyamotoi*. Diagnostic testing is limited; however, the treatment thus far is similar to that of Lyme disease.

Remember tick-borne co-infections are the norm, not the exception.

4th video - Discover treatment options



This fourth brief video summarizes several treatment options.

[Here is the fourth video.](#)

Transcript for treatment decisions

Unfortunately, there simply isn't a one-size-fits-all treatment protocol for patients infected with Lyme disease and/or co-infections. This is why it's critical for physicians treating Lyme disease to invest time with patients, thoroughly understand their medical history and to closely monitor symptoms and treatment response. With that in mind, there are currently two different treatment approaches for Lyme disease.

The Infectious Disease Society of America (IDSA) and the International Lyme and Associated Diseases Society (ILADS) has each published their own set of evidence-based treatment guidelines. IDSA guidelines recommend a short course of antibiotics, typically 14 to 30 days. IDSA argues that the *Borrelia burgdorferi* bacteria does not persist in a patient beyond this timeframe and that lingering symptoms are the result of an ongoing immune response and not the result of an active infection. It also cites scientific evidence claiming treatments

beyond 30 days are ineffective, unnecessary and even dangerous.

IDSA physicians will stop treatment after 30 days even if symptoms remain. However, there is an additional 30 days of treatment recommended for patients with Lyme arthritis.

On the contrary, ILADS offers its own scientific data to show that a longer course of antibiotics is required to eradicate the bacteria. ILADS recognizes that a month of treatment may be sufficient for patients in the acute stage of Lyme disease but in cases where the spirochete has disseminated and the disease has advanced, a 30-day treatment regimen is inadequate.

ILADS guidelines recommend additional antibiotics until a patient's symptoms have been resolved. Treating Lyme disease and its advanced stage can be complicated based on the complexity of the organism itself, the differences in each patient's immune system, the length of time infected and the possible presence of other co-infections transmitted

by the same tick. However, there are several choices in treating Lyme disease which include oral, intravenous and intramuscular antibiotic options.

Other options may include, sequential antibiotic therapy, higher doses of antibiotics, taking antibiotics for a longer period of time, a combination of antibiotics, retreatment, as well as, diagnosing and treating co-infections. Some specific antibiotics used in treating Lyme disease are doxycycline, minocycline, amoxicillin, Cefuroxime, azithromycin and clarithromycin.

There are additional actions that may also aid in treating Lyme disease such as avoiding alcohol, simple and processed sugars, exercising is tolerated, counseling for Jarish herxheimer reaction, managing symptoms, monitoring and reducing the risk of an adverse event and reducing stress.

However, there is a chance of side effects such as *Clostridium difficile*-associated diarrhea. It is important to note the possible benefit of taking probiotics when treating Lyme disease.

n one study, probiotic use significantly reduced the risk of developing C. diff by 60.5%. Other steps include measures of blood counts, chemistry's and liver function tests.

In some cases a specialist might be advised. Remember choosing a treatment option should be a shared decision between physicians and their patients; also there should be regular follow-up visits to re-assess a patient's response to treatment.

News



There has been a wealth of new information published by our researchers and clinical community. Dr. Cameron has shared these new findings thorough more than 600 Inside Lyme Science blogs and podcasts. Check out his [blogs](#) and [podcasts](#).

You can keep up with the news by signing up for his newsletter.

Book readings and discussions



Dr. Cameron has recorded a series of book readings and discussions to expand on his book. Check out his readings and discussions.

Connect with Dr. Cameron



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