



International Lyme and Associated Diseases Society

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TOP TEN TIPS TO PREVENT CHRONIC LYME DISEASE

For those who suffer from chronic Lyme disease, life is never the same again. People with chronic Lyme can have many debilitating symptoms, including severe fatigue, anxiety, headaches, and joint pains. Typically, chronic Lyme patients have a poorer quality of life than patients with diabetes or a heart condition.

The fact is that Lyme is a complex disease that can be highly difficult to diagnose. Reliable diagnostic tests are not yet available which leaves many—patients and physicians alike—relying on the so-called “telltale signs” of Lyme disease: discovery of a tick on the skin, a bull’s-eye rash, and possibly joint pain. However, ILADS research indicates only 50%-60% of patients typically recall a tick bite; the rash is reported in only 35% to 60% of patients; and joint swelling typically occurs in only 20% to 30% of patients. And given the prevalent use of over-the-counter anti-inflammatory medications such as Ibuprofen, joint inflammation is often masked.

Based on these statistics, a significant number of people who contract Lyme disease are misdiagnosed during the early stages of the disease, leading to a chronic form which can prove even more difficult to diagnose and treat. Lyme disease is often referred to as the “great imitator” because it mimics other conditions, often causing patients to suffer a complicated maze of doctors in search of appropriate treatment. ILADS is committed to the prevention of chronic Lyme disease. The following tips are designed to offer guidance and minimize the risk of contracting chronic Lyme disease.

1. Know that Lyme disease is a nationwide problem

Contrary to popular belief, Lyme disease is not just an “East Coast” problem. In fact, in the last ten years, ticks known to carry Lyme disease have been identified in all 50 states and worldwide. Although the deer tick is considered the traditional source of Lyme Disease, new tick species such as the Lonestar tick and a pacific coast tick, have been found to carry *Borrelia burgdorferi*, the corkscrew-shaped bacterium that causes Lyme disease.

Avoiding a tick bite remains the first step in preventing chronic Lyme disease. One needn't have been “hiking in the woods” in order to be bitten by a tick. There can be ticks wherever there is grass or vegetation, and tick bites can happen any time of year. Spraying one’s clothes with DEET-containing insecticide, wearing long sleeves and long pants, and “tucking pants into socks”, continue to be the best ways to avoid ticks attaching to the skin. But don’t forget the post-walk body check.

2. Check your tick facts

Ticks can vary in size from a poppy size nymphal tick to the sesame seed size adult tick. The ticks can carry other infectious agents beside the spirochete that causes Lyme disease, including Ehrlichia, Anaplasmosis, Babesia, and Bartonella. Lyme disease can sometimes be hard to cure if these other infections are not treated at the same time.

3. Show your doctor every rash

The bull’s-eye rash is the most famous, but there are many other types of rashes associated with Lyme disease. In fact, Lyme disease rashes can be mistaken for spider bites or skin infections. Take photos and make sure a medical professional sees the rash before it fades.

4. Don’t assume that you can’t have Lyme disease if you don’t have a rash

Lyme disease is difficult to diagnose without a rash, Bell’s palsy, arthritis, or meningitis, but you can still have Lyme and not have any of those signs or symptoms. Many people react differently to the infection and experience fatigue, headaches, irritability, anxiety, crying, sleep disturbance, poor memory and concentration, chest pain, palpitations, lightheadedness, joint pain, numbness and tingling.

5. Do not rely on test results

Currently there is no reliable test to determine if someone has contracted Lyme disease or is cured of it. False positives and false negatives often occur, though false negatives are far more common. In fact, some studies indicate up to 50% of the patients tested for Lyme disease receive false negative results. As a result, the CDC relies on physicians to make a clinical diagnosis based on a patient's symptoms, health history, and exposure risks. Doctors who are experienced in recognizing Lyme disease will treat when symptoms typical of the illness are present, even without a positive test, in an effort to prevent the development of chronic Lyme disease.

6. Be aware of similar conditions

Chronic Lyme disease is called the "great imitator" because it is often misdiagnosed as another condition such as multiple sclerosis, fibromyalgia, chronic fatigue, or anxiety. Misdiagnosis is a common experience for patients with chronic Lyme disease. Treatments that work for these other illnesses are not appropriate for treating Lyme disease. Currently, the only effective treatment for Lyme disease is antibiotics. Ask your doctor to carefully evaluate you for Lyme disease even if your tests are negative.

7. Avoid taking a "Wait and See" approach to treatment

Up to fifty percent of ticks in Lyme-endemic areas are infected with Lyme or other tick-borne diseases. With odds like that, if you have proof or a high suspicion that you've been bitten by a tick, taking a "wait and see" approach to deciding whether to treat the disease has risks. The onset of Lyme disease symptoms can be easily overlooked or mistaken for other illnesses. Once symptoms are more evident the disease may have already entered the central nervous system, and could be hard to cure. This is one case in which an ounce of prevention really *is* worth a pound of cure.

8. Don't be afraid to get a second opinion

Recognize that opinions on how to diagnose and treat Lyme disease vary widely among physicians. It is worth getting a second or even a third opinion, especially if you are symptomatic and your doctor advises *not* to treat, or symptoms recur or persist after treatment. Keep in mind that your physician may focus too narrowly on diagnosing and treating a single symptom. For example, a physician may diagnose a pain in your knee as "arthritis", and not see this as just one part of a larger set of symptoms that adds up to a diagnosis of Lyme disease, which requires different treatment.

9. Know your treatment options

Work with your doctor to identify the appropriate treatment option if your symptoms persist. There is more than one type of antibiotic available. Longer treatment is also an option. You should also work with your doctor to make sure you don't have another condition.

10. Expect success

You should expect to get better. You should not accept "watchful waiting" – the practice of stopping antibiotic treatment before you are well and then waiting for symptoms to clear on their own. Some doctors advocate stopping Lyme treatment while the patient is still symptomatic and then hoping that he or she will eventually recover without further treatment. Government trials have identified a number of individuals whose symptoms did not clear when treatment was cut off prematurely. There are doctors who feel your symptoms will clear with further antibiotic treatment.

Support by Turn the Corner Foundation

Turn the Corner Foundation (TTCF) is dedicated to the support of research, education, awareness and innovative treatments for Lyme disease and other tick-borne diseases. Since its inception, TTCF has organized and supported countless programs that address Lyme disease education, diagnosis and treatment.

About ILADS

ILADS is a nonprofit, international, multidisciplinary medical society, dedicated to the diagnosis and appropriate treatment of Lyme and its associated diseases. ILADS promotes understanding of tick-borne diseases through research and education and strongly supports physicians and other health care professionals dedicated to advancing the standard of care for Lyme and its associated diseases.

For more information visit the ILADS website at <http://www.ilads.org/>