Reported Cases of Lyme Disease -- United States, 2011





Lyme disease spreads only by a tick bite. Though the bite may go unnoticed, the infection usually starts with a painless, spreading rash where the tick had attached itself to the skin.

Lyme disease is an infection spread by the bite of certain types of ticks. If caught and treated early, the infection most often clears quickly. If not found until the later stages of infection, people with Lyme disease are more likely to still have symptoms (what you feel) after treatment. These include fatigue (feeling very tired), poor sleep, and muscle and joint pain.

Fast Facts

- Lyme disease spreads only by a tick bite. Though the bite may go unnoticed, the infection usually starts with a painless, spreading rash where the tick had attached itself to the skin.
- Noticing the early signs of Lyme disease and getting prompt treatment when they occur greatly reduces the severity and length of symptoms.
- Even when the infection is found much later, antibiotic treatment is still successful for most people.

What is Lyme disease?

Lyme disease is an infection resulting from the bacteria, *Borrelia burgdorferi*, which enter the body when certain infected ticks bite. These blacklegged ticks are most often deer ticks. There are three stages of infection.

In the **early localized stage**, a rash, called erythema migrans, appears at the site of the tick bite from three days to a few weeks later. The rash starts as a small red mark and over days slowly grows to at least two inches wide. It can spread to 10 or more inches, sometimes with a ring or bull's-eye shape.



Most often, the rash does not hurt or itch.

About 10-25 percent of the time, the rash where the tick bit goes unnoticed. If left untreated, the infection may spread to other parts of the body in days to weeks. This is called the **early disseminated stage**. The person infected may have many signs and symptoms, including:

- More than one rash
- Fever
- Joint pain and muscle pain
- Headache



The erythema migrans rash starts as a small red mark. Over the next days, it slowly enlarges to two or more inches wide.

In about 20 percent of cases, the infection can attack the nervous system. This can cause very bad headache and stiff neck,

paralysis of the muscles of the face or painful inflammation of nerves. If the infection reaches the heart, as it does in about 5 percent of cases at this stage, the heartbeat may slow too much (known as heart block). Some people will have no symptoms.

The **late stage** may occur months to even years after the bite, mostly in those who did not get early treatment. At this stage, the infection can affect the joints (Lyme arthritis), causing pain and swelling of one or both knees. Less often, Lyme arthritis can involve other, mostly large, joints.

Late-stage infection rarely can also harm the nervous system. It may affect the peripheral nerves (nerves outside the brain and spinal cord), leading to numbness or tingling or, less often, weakness. If the infection affects the brain, it may lead to trouble with memory and concentration.

What causes Lyme disease?

Lyme disease results from the spread of *Borrelia burgdorferi* bacteria living inside infected ticks. These small ticks can attach to human skin and go unnoticed, feeding for a few days. During that time, the bacteria pass from the tick into the person, before the tick dislodges.

Other infections spread by ticks may occur at the same time (co-infection) or separate from Lyme disease. These also require prompt medical care.

Who gets Lyme disease?

In the United States, Lyme disease occurs mostly in the Northeast and Middle Atlantic states from Virginia northward, the upper Midwest and, to a lesser degree, in Northern California and the Pacific Northwest. The illness is named after the town of Old Lyme, Connecticut, where the first cases of Lyme disease were found in 1975.

People most at risk are those who spend time outdoors in rural or suburban sections of these regions, mainly at certain times of the year. More infections occur in the late spring and early summer. Those times are when the tiny (poppy seed sized) immature form of the tick (nymph) is feeding. A second, smaller wave of Lyme disease



occurs in the fall and in early to midspring when the larger (sesame seed sized) adult tick feeds. The risk of tick bites is lower during the late summer after the nymph ticks become inactive, and in the winter. Cold weather (below about 50 degrees F) and snowfall make the adult ticks dormant.

How is Lyme disease diagnosed?

The most accurate way to detect Lyme disease is with two blood tests. The first is an enzyme-linked immunosorbent assay (often referred to as ELISA). This test looks for certain antibodies (immune proteins) that are the immune system's response to the infection. The second test, a Western blot, confirms positive (abnormal) or borderline positive ELISA results.

Sometimes, these lab tests are wrong. A person who does not have Lyme disease may have a false positive on a blood test, or someone who has Lyme disease may have a normal result, which is called a false negative. (A false negative is common in the early weeks of the infection, but at later stages is rare.) Therefore, only patients who show possible symptoms of the disease should get lab tests for Lyme disease.

How is Lyme disease treated?

Treatment of Lyme disease is with certain antibiotics. In most cases, early-stage Lyme disease is treated successfully with two to three weeks of oral (by mouth) antibiotics. Most cases of early-stage Lyme disease need just two or three weeks of antibiotics, most experts agree. However, patients with arthritis (swelling of a joint) need longer treatment (four weeks) with oral antibiotics. If arthritis persists, they may need a second four-week course of oral or intravenous (often called IV) antibiotics. Infection involving the nervous system or heart also may require IV antibiotics.

Even when antibiotic treatment does not start until the later stages, it is still successful in most patients.

However, early detection and treatment are important. People are more likely to have lingering symptoms after treatment if they do not get treatment promptly. These symptoms include fatigue, poor sleep, and muscle and joint pain. The name for this set of ongoing symptoms is post-Lyme disease syndrome.

The cause of post-Lyme disease syndrome is not known. Symptoms are similar to those that can occur after other infections and stressors to the body. Treatment with more antibiotics beyond the first standard treatment has not been proven to be of benefit. Only people with ongoing active infection (which is rare after earlier recommended antibiotic treatment) should receive additional antibiotic treatment. Most people with this syndrome will improve over time.

Prevention

Ticks do not jump. Instead, they must brush onto a person after direct contact. To reduce the risk of Lyme disease:

- Avoid ticks' favorite habitats. These include tall grass, leaf-covered ground, and brush. Instead, stay on open paths, cut grass or sand.
- **Dress properly.** Wear light-colored clothing to make it easier to see ticks on you. When possible, wear closed shoes and long pants. Tuck the hems of long pants into socks to block skin access.



- Use insecticide. Spray your skin and clothes with insecticides containing DEET when outdoors.
- **Check your body for ticks after being outdoors.** Removing ticks within 24-36 hours of tick attachment most often will prevent spread of the disease. If you find a tick on your skin, consult your doctor if you do not know how long it has been there or it is likely to have been there longer than one or two days.
- **Remove a tick properly.** As soon as you see a tick, remove it by its head using fine-tipped tweezers.

There is no vaccine available against Lyme disease.

Living with Lyme disease

Until you feel better, get proper rest and pace your activities. Then slowly return to normal activity. After you finish treatment, follow up with your doctor.

For those who have lingering symptoms after treatment, a healthy lifestyle becomes even more important. This includes exercise, good nutrition and enough rest. Again, follow-up with your doctor is important to help in your recovery.

Points to remember

- Treatment of Lyme disease is most often successful.
- Blood tests may be negative (normal) in the first weeks of infection. Thus, early-stage Lyme disease should be diagnosed and treated based on a person's exposure risk and typical symptoms.
- When symptoms linger after treatment, proper self-care and physician follow-up will help in recovery.
- Reduce the risk of Lyme disease by avoiding tick habitats at certain times of the year, checking your body for ticks and promptly removing any tick you find.

The rheumatologist's role in treating Lyme disease

Rheumatologists are doctors who are experts in diagnosing and treating diseases that can affect joints and muscles, including infections such as Lyme disease. Primary care physicians and infectious disease doctors also diagnose and treat people with Lyme disease.

To find a rheumatologist

For more information about rheumatologists, click here.

For a listing of rheumatologists in your area, click here.



For additional Information

The American College of Rheumatology has compiled this list to give you a starting point for your own additional research. The ACR does not endorse or maintain these web sites, and is not responsible for any information or claims provided on them. It is always best to talk with your rheumatologist for more information and before making any decisions about your care.

American Lyme Disease Foundation

www.aldf.com

Centers for Disease Control and Prevention <u>www.cdc.gov/lyme</u>

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