Lyme Disease

Lyme disease is an infection conveyed by the bite of certain types of ticks. If caught and treated early, the infection usually clears quickly. In the later stages of infection, those with Lyme disease are more likely to experience symptoms after treatment such as fatigue, poor sleep, and muscle and joint pain.

Fast facts
- Lyme disease can be spread only by a tick bite. While the bite itself may go unnoticed, the infection usually starts with a painless, spreading rash where the tick was attached to the skin.
- Being aware of the early signs of Lyme disease and getting prompt treatment when it does occur dramatically reduces the severity and duration of symptoms.
- Even when the infection is detected much later, antibiotic treatment is still successful for most people.

What is Lyme disease?
Lyme disease is an infection caused by the bacteria, *Borrelia burgdorferi*, which enters the body when certain ticks bite. In its early localized stage, a skin rash, called erythema migrans, appears at the location of the tick bite from three days to several weeks later. The rash starts as a small red mark and gradually grows in width to at least two inches. It can spread 10 or more inches.

About 10-25 percent of the time, the initial rash goes unnoticed. If left untreated, the infection may then spread to other parts of the body within days to weeks. This is called the early disseminated stage of infection. The person infected may develop many symptoms including multiple skin rashes, fever, joint pain, muscle pain and headaches.

In approximately 20 percent of cases, the infection can attack the nervous system, causing severe 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 heart beat may slow abnormally (known as heart block). Still other individuals will have no symptoms at all.

**Late stage** infection may occur months to even years after the bite, mostly in those who were not treated early. At this stage, the infection can affect the joints (Lyme arthritis), causing swelling of one or both knees. Less often, Lyme arthritis can involve other, mostly large, joints of the body. Late stage infection more rarely can also harm the nervous system. Peripheral nerves may be affected, leading to numbness or tingling or, less often, weakness. Infection of the brain may lead to difficulty with memory and concentration.

**What causes Lyme disease?**
Lyme disease is caused by the transmission of *Borrelia burgdorferi* bacteria living inside infected ticks. These small ticks can go unnoticed, attaching to the skin and feeding for several days before dislodging.

Other infections transmitted by ticks may occur at the same time (co-infection) or separate from Lyme disease. These also require prompt medical attention for proper diagnosis and treatment.

**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 region. The illness is named after the town of Old Lyme, Connecticut where the first cases of Lyme disease were recognized in 1975.

People most at risk are those who spend time outdoors in rural or suburban sections of these regions. More infections occur in the late spring and early summer months when the tiny (poppy seed sized) nymphal form of the tick is feeding. A second smaller wave of Lyme disease occurs in the fall when the adult tick feeds. The risk of tick bites is lower during the late summer after the nymphal ticks have become inactive, and in the winter when cold (below about 45 degrees F) and snowfall make the adult ticks temporarily dormant.

**How is Lyme disease diagnosed?**
To optimize diagnostic accuracy, the Centers for Disease Control has recommended a two-step approach that uses an ELISA blood test to look for evidence of particular antibodies in the immune system’s response to the infection followed by a second test (Western blot) to confirm a borderline or positive results.
In certain circumstances, a person who does not have Lyme disease may have a false positive on a blood test or someone who has Lyme disease may register a false negative (this occurs commonly in the early weeks of the infection or more rarely later). Therefore, lab testing should be used only when patients show possible symptoms of the disease.

**How is Lyme disease treated?**

In the majority of cases, early stage Lyme disease is treated successfully with two to three weeks of oral antibiotics. Early infection involving the nervous system or heart may require intravenous antibiotics. Even when the infection is detected after significant delay or at its later stages, antibiotic treatment is still successful in most patients.

However, early diagnosis remains important. Those individuals with early stage Lyme disease who remain undiagnosed for extended periods of weeks to months or those who have late stage infection of the nervous system are more likely to have a variety of lingering symptoms such as fatigue, poor sleep, and muscle and joint pain even after treatment.

**Prevention**

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

- Avoid ticks’ favorite habitats such as tall grass, leaf-covered ground, and brush.
- Stay on open pathways, cut grass or sand environments, which carry a much lower risk of tick exposure.
- Dress appropriately. Wear light colored clothing for early detection of ticks, and, when feasible, tuck the hems of long pants into socks to block skin access.
- Spray the skin with insecticides containing DEET to reduce the chance of a tick bite.
- Conduct tick checks regularly. Removing ticks with a fine-tipped tweezers within 24-36 hours of tick attachment usually will prevent disease transmission. If a tick is found and the duration of attachment is likely to be greater than 24-36 hours or is unknown, consult your physician.

There is no vaccination available against Lyme disease.

**Living with Lyme disease: broader health impacts**

For those who have lingering symptoms following treatment, general measures of good health become even more important. These include exercise, good nutrition, and care of any emotional problems that may coexist or develop as a result of prolonged illness. Proper rest and pacing of activities as well as adjustment of schedule and expectations is advised. This should be followed by a gradual return to normal activity. Physician follow-up is also strongly recommended. Further treatment with antibiotics should be reserved for the rare, on-going active infection.

**Points to remember**

- Lyme disease is usually successfully treated once recognized. Blood tests may be negative in the first weeks of infection. Therefore early stage Lyme disease should be diagnosed and treated based on an individual's exposure risk and typical symptoms.
• When symptoms linger after treatment, exercise, good nutrition, attention to other measures that promote good health and physician follow-up will assist in recovery.
• The risk of Lyme disease can be reduced by avoiding tick habitats at specific times of the year, having regular tick checks and promptly removing any tick found.

The role of the rheumatologist
Rheumatologists are specialists in musculoskeletal disorders including infections that can affect joints and muscles such as Lyme disease. Primary care physicians and infectious disease specialists 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 more information
The American Lyme Disease Foundation has an informative website about Lyme disease and other tick-borne infections at www.aldf.com or can be reached by calling 800-876-LYME.

The Centers for Disease Control and Prevention has a website devoted to information on Lyme disease at: http://www.cdc.gov/ncidod/dvbid/lyme/index.htm.

Updated June 2008
Written by Robert Kalish, MD, and reviewed by the American College of Rheumatology Patient Education Task Force.

This patient fact sheet is provided for general education only. Individuals should consult a qualified health care provider for professional medical advice, diagnoses and treatment of a medical or health condition.

© 2010 American College of Rheumatology