

*Fifth Edition April 2009*

# **Lyme Disease**

**and associated diseases**

## THE BASICS

**A plain-language introduction to  
tick-borne diseases**

*by*

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# Lyme Disease

## and associated tick-borne diseases

Fifth edition March 2009

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The information in this publication is true and complete to the best of our knowledge. This booklet is intended only as an introduction to the subject of tick-borne diseases and is not intended to be a substitute for sound medical advice from your physician.

All information presented as fact is based on published medical literature. A version of this booklet with all references is available from LDASEPA and on-line at [www.LymePa.org](http://www.LymePa.org). Some information is speculative and is clearly indicated as such. Because new research is adding to the knowledge-base of tick-borne diseases, no publication can hope to be completely up-to-date. We intend to revise this booklet when necessary, but the reader will benefit from updated information available on the Web sites listed in the Resources section.

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## THE BASICS

*Answers to the most commonly-asked questions*

### **Q. What is Lyme disease?**

A. Lyme disease is a bacterial infection, most commonly contracted from a tick bite, that may initially cause a flu-like sickness. Untreated, or inadequately treated, it may cause long-term, persistent illness that can affect many systems of the body. Other tick-borne diseases are often contracted at the same time.

### **Q. How do you get it?**

A. Lyme Disease (LD) is spread primarily through the bite of the deer tick in the eastern U.S., and the black-legged tick in the western U.S. The Lone Star tick, prevalent in the South and Midwest and spreading elsewhere, has also been associated with Lyme disease. Some researchers believe that other ticks and some biting insects such as mosquitoes, fleas, biting flies, and lice may also transmit LD. Babies may be born infected if the mother is infected, or possibly acquire it through breast milk. A blood transfusion with Lyme-infected blood may transmit the disease to the recipient. Some specialist medical researchers believe that Lyme, or other tick-borne diseases, can be sexually transmitted, although there has never been any research to confirm or deny it. Lyme spirochetes have been found in many bodily fluids.

### **Q. How do I know if I have Lyme disease?**

A. This can be a problem because the symptoms of LD are very similar to those of many common infections, and mimic some of the symptoms of other diseases. One sign that is almost unmistakable is the development of a bull's eye rash around the site of a tick bite. *If you have this*

*rash, you have Lyme disease.* The bull's eye rash varies considerably in different people, but it is typically centered on the tick bite and may range from a fraction of an inch to many inches in diameter. It may be colored anywhere from a mild red to a deep purple. It may appear in a few days or even several weeks after the bite. It may spread to other areas of the body, or there may be additional rashes far from the primary one. The classic rash has concentric areas of lighter and darker colors and expands with time, but the rash is not always in a bull's eye form. It is usually painless, but it may be warm to the touch and may itch. Typically it is flat, but some people have raised areas or bumps in the rash.

Unfortunately, not everyone develops a rash, and many people fail to notice it if it is in a hard-to-see location, such as the scalp. Fewer than half the people who develop LD recall a rash or a tick bite.

Other symptoms may appear at the same time. These often mimic a cold or flu, with fever, headache, muscle and joint pains, tingling or numbness, and/or general fatigue. Early Lyme can produce a wide range of symptoms, or no symptoms at all, and is different in each person. The varied symptoms may change rapidly, sometimes within hours.

The symptoms may disappear in a few days or a week (even without treatment), or may be so minor that the infected person barely notices them. Since flu season runs during the winter months, and most LD infections occur during the other seasons, any case of "flu" in warm weather should be considered suspect.

Even if these initial symptoms subside, the bacteria can remain in your body and may harm you later. In other cases, symptoms become increasingly severe, requiring prompt medical attention. In persistent Lyme disease, symptoms are most often severe fatigue, pains that seem to have no obvious cause, and neurological and/or psychiatric problems. The disease may involve multiple body systems and organs. Symptoms may be complicated by other tick-borne co-infections acquired from the same tick bite or another tick bite.

Doctors with experience in treating Lyme disease often prescribe no less than six weeks of antibiotic treatment for a tick bite with a bull's eye rash. If your doctor does not agree with this approach, it may be prudent to search for a doctor who will support extended treatment.

#### **Q. Is there a test for LD?**

A. According to many experts, there is no reliable test for Lyme disease at this time. Your doctor should base his or her diagnosis on your symptoms, medical history, and your exposure to ticks. Doctors should not

rely solely on tests. There are several blood tests available, but all have problems. The blood test typically used by most family doctors, called an ELISA (or Lyme titer) test, means nothing if it is negative, and it rarely indicates infection if it is performed too early (2 to 6 weeks after the tick bite).

Patients with persistent LD seldom have a positive ELISA test, possibly because they have ceased to produce the antibodies the test looks for. Many experts believe that the ELISA test is only about 30-60% accurate. The ELISA test is not based on the specific Lyme bacteria strain that is most useful for accurate diagnosis. While a positive ELISA test is a reasonably reliable indication of infection, a negative test is useless.

There are other tests that may be more accurate. The Western blot test for Lyme disease often shows infection when an ELISA test does not. Unfortunately, the U.S. Centers for Disease Control (CDC) have set arbitrary criteria for considering a Western blot test as positive for LD. These criteria were established for statistical analysis of the spread of the disease and were not intended to guide doctors in their diagnosis and treatment. The CDC surveillance criteria are very strict and miss many people with LD. Doctors who use only the CDC guidelines to decide whether or not to treat leave many infected people without proper antibiotic treatment. Even if the test results are not positive by CDC standards, any positive Lyme-specific "bands" are useful indicators of infection.

Another test, PCR analysis, looks for the DNA of the Lyme bacteria in blood, urine, or tissue. Multiple tests are usually required before a sample is obtained that contains the bacteria. However, in recent years PCR testing has become extremely reliable when positive. Most doctors are unaware of this test.

Medical textbooks, the FDA, and the CDC emphasize that LD is a *clinical diagnosis*, which means that the doctor should examine the patient for typical LD signs, listen to the patient's history and description of his or her symptoms and use this information to make a determination. Blood tests are usually done at the same time, but should not be relied upon. According to ILADS (the International Lyme and Associated Diseases Society), if the doctor suspects LD, and sees little reason to believe the patient has some other disease, he or she should begin antibiotic treatment without delay. Of course, doctors should also perform general blood and other tests to rule out other diseases or conditions.

**Q. Are all testing labs the same?**

A. No, they are not. Some labs have made special efforts to focus on tick-borne disease testing and they use procedures that make their tests more reliable and sensitive to LD. Use the resources in the back of this booklet to help you identify laboratories that utilize tests that are more sensitive to tick-borne disease organisms, and urge your doctor to send your blood sample to one of the specialist laboratories. Test kit request forms may be available on the laboratory's web site.

**Q. I had a bull's eye rash and other symptoms, but my doctor said my blood tests showed I didn't have LD, so it must have been something else, right?**

A. Almost certainly not! This scenario has caused many people to needlessly suffer for months or years. Left untreated, LD can be a devastating disease. There are few conditions that mimic the LD rash. Lyme-literate doctors suggest starting immediate antibiotic treatment, regardless of the results of any tests.

Often a person suffering from chronic, unsuspected Lyme disease will be diagnosed as having something else, such as chronic fatigue syndrome, fibromyalgia, lupus, multiple sclerosis, Parkinson's disease, Alzheimer's disease, ALS, Crohn's disease, carpal tunnel syndrome, temporomandibular joint disorder (TMJ), and a wide variety of psychological or psychiatric disorders. Doctors often mistake tick bites for spider bites, but spider bites are actually uncommon. In areas where LD is prevalent, it should be seriously considered before a doctor denies antibiotic treatment.

**Q. What happens if LD is not properly treated?**

A. This varies tremendously among individuals. Some people may never have a recurrence of symptoms, while others may become seriously disabled from LD that is untreated or inadequately treated. Serious symptoms can appear immediately or they could take months or years to develop. The most common symptoms are unrelenting fatigue; joint or muscle pain (particularly in the neck, knee, back, or foot); vision or hearing abnormalities; numbness or tingling, particularly at the extremities; facial paralysis; heart damage; psychological disturbances; and stomach problems. (There is an extensive checklist of symptoms in the back of this booklet. Consider bringing this list to your doctor if you suspect you have LD.)

Untreated LD can result in neurological disorders, crippling arthritis, blindness, deafness, psychiatric or psychological disorders, or death.

**Q. What is the proper treatment for Lyme disease?**

A. Antibiotic treatment is the simple answer. But the detailed answer is unknown. If they are treated immediately after a tick bite, many patients seem to obtain elimination of all symptoms after a course of six weeks of an oral antibiotic like doxycycline. However, it is not known if this treatment permanently cures the disease. If you had a tick bite and a rash, knowledgeable physicians feel that you should be treated with antibiotics as long as symptoms persist. If there is any recurrence of symptoms after treatment, your doctor should put you on another course of antibiotics.

A patient who seems to be symptom-free should be vigilant in watching for any recurrence, and so should his or her doctor. Relapses do occur.

At the other end of the spectrum, some patients find no relief at all from a short course of antibiotics, particularly if they have co-infections. Many long-term LD patients given the standard oral antibiotic treatment seem to do fine for years and then suddenly experience the same or new symptoms. Often a stressful life event such as a jarring accident, head injury, surgery, divorce, or a death in the family can trigger reemergence of symptoms mimicking a new infection. Some patients obtain relief with another course of oral antibiotics, while others require long-term treatment with oral, intravenous (IV), or injected antibiotics. Because of the complexity of the Lyme bacteria's life cycle, combinations of antibiotics may be necessary.

In addition to medication, Lyme patients need to develop a good program of exercise and nutrition. Patients on antibiotics need to take acidophilus, which replaces the good bacteria (killed by antibiotics) that are necessary for the body's digestive system to function properly. Many patients also take supplements that help boost the immune system. Consult with your physician on all non-prescription treatments.

**Q. How does my doctor know when I am cured?**

A. Many doctors who treat LD patients avoid using the term "cured" because of the possibility of a relapse in the future. However, most Lyme-literate doctors believe that treatment of persistent infection should continue for at least two months after all symptoms have disappeared. Both the patient and the doctor should be prepared to resume treatment if symptoms recur.

**Q. Isn't there a vaccine for Lyme disease?**

A. There was one, but the manufacturer took it off the market in 2002. Evidence indicated that people with a certain gene might develop an autoimmune arthritic disease from the vaccine. About 30% of the population has this gene, and taking the vaccine could result in severe arthritis. There is no known cure for this condition. Some doctors have seen cases where “cured” or previously undiagnosed LD is reactivated in patients who were vaccinated. The vaccine offered no protection against other tick-borne disease co-infections that frequently accompany LD.

The vaccine was only about 80% effective and it was not known how long the partial immunity lasted.

Perhaps a safe and effective vaccine will be developed in the future, but for now, the only way to avoid contracting Lyme disease is to avoid ticks and the other possible sources of infection.

**Q. Once you have had Lyme disease, you're immune, right?**

A. No. You can get Lyme over and over from new tick bites. Each new tick bite can infect you with a new case of Lyme disease or other tick-borne diseases. Some Lyme doctors believe that each subsequent infection makes symptoms more severe and treatment more difficult.

**Q. Why haven't I heard much about Lyme disease until recently?**

A. Lyme disease and its variants have been known throughout the world for at least 100 years (often by different names). There are hundreds of identified strains of the bacteria that causes LD, dozens of them in the U.S. There is even evidence that prehistoric people were infected with it.

Also, patients with LD may have been undiagnosed or misdiagnosed before doctors became more knowledgeable.

However, it does seem that Lyme disease is much more prevalent now than it was in the past. The main “reservoir” for Lyme disease is the white-footed mouse and sometimes other small animals. The Lyme spirochetes live in the blood of the mouse and are passed to a tick when it feeds on an infected mouse. The white-tailed deer is a major host for the ticks that carry LD, and the deer ensure that the ticks have a comfortable place to live and breed. Many areas of the U.S. have had a tremendous increase in the deer population in recent years, so there may be many more ticks in the environment. The loss of diversity in our

wildlife means that ticks are more likely to attach to the mice that harbor the Lyme bacteria. Birds are known to transport ticks to new areas.

**Q. Why don't doctors know more about Lyme disease?**

A. Some doctors are very up-to-date on the latest research on LD, but many are not. Many doctors are taught that LD is rare and easily-cured and they may think that it is not a serious disease. With thousands of diseases and conditions to learn about, Lyme doesn't seem to rank very high with the majority of doctors, even though it is the most common vector-borne infectious disease in the U.S. Nevertheless, it is a major medical problem in the U.S., resulting in billions of dollars in expenses and lost time from work. Over 20,000 new cases were reported to the CDC every year since 2002, and the CDC estimates that at least ten times that many cases that meet its criteria are not reported.

**Q. What can be done to address these issues of poor tests and uninformed doctors?**

A. Organizations such as the International Lyme and Associated Diseases Society (ILADS, an organization of LD health professionals), the Lyme Disease Association, the Lyme Disease Association of Southeastern Pennsylvania, California Lyme Disease Association, and many others have programs that are aimed at educating the public and doctors on the latest information about the disease. These organizations support federal legislation that would fund research into prevention, more accurate tests, and improved treatments for Lyme disease and co-infections.

**Q. What are these “co-infections” and “associated diseases?”**

A. The ticks that carry the Lyme bacteria also often carry microorganisms that cause other diseases. The most common “co-infections” are anaplasmosis, ehrlichiosis, babesiosis, bartonella, and Rocky Mountain spotted fever. Anaplasmosis, ehrlichiosis, bartonella, and Rocky Mountain spotted fever may be cured by some of the same antibiotics that are prescribed for Lyme disease. But babesiosis is a different type of disease, caused by a blood parasite and not a bacterium. Antibiotics alone are not effective against babesiosis.

New organisms are being discovered in ticks all the time. Their role in human illness is not yet known.

Few doctors are familiar with these diseases. They may fail to recognize the symptoms or test for these diseases, so many people are suffering

from untreated infections. The lab tests for these co-infections have many of the same problems as LD tests. Often, it is this combination of diseases that makes the patient so mystifyingly ill and unresponsive to treatment.

**Q. What are the symptoms of anaplasmosis or ehrlichiosis?**

A. Like Lyme disease, anaplasmosis and ehrlichiosis infections peak during May, June, and July and the symptoms typically appear from a week to a month after infection. The initial symptoms are flu-like and can include high fever, chills, headache, fatigue, and general achiness. Fewer than half of infected people report a rash. The rash is different from a Lyme disease rash; it is usually smaller and may have raised areas. The rash is more common in children than adults. Children may also suffer from swelling of the hands and feet. Other symptoms may develop later, including nausea, diarrhea or constipation, loss of appetite, cough, stiff neck, confusion, and weight loss. Untreated, the disease can sometimes be fatal in a few weeks, especially in children.

**Q. How are anaplasmosis and ehrlichiosis diagnosed?**

A. There are blood tests for anaplasmosis and ehrlichiosis, which vary in accuracy and reliability depending on when the test is performed. It is difficult to obtain an accurate test result during the first few weeks after infection.

**Q. How are anaplasmosis and ehrlichiosis treated?**

A. Anaplasmosis and Ehrlichiosis are usually treated with doxycycline. Most cases respond quickly when diagnosed and treated promptly. Like Lyme disease, you can get these diseases over and over again from new tick bites.

**Q. What are the symptoms of babesiosis?**

A. People with babesiosis sometimes have no symptoms at all. However, it can be life-threatening for someone with a suppressed immune system. It is also more serious for people over age 50. Symptoms are often the same as for Lyme disease (see list in the back of this booklet), but there may also be a very high fever of up to 104°F, and anemia. Night sweats, chills, severe headaches, fatigue, and sleep disturbances are common. You can get babesiosis from a blood transfusion from an infected donor.

**Q. How is babesiosis diagnosed?**

A. There are blood tests, but the test reliability declines after a few weeks of infection. These tests suffer from the same lack of sensitivity that plagues Lyme disease testing. PCR tests for babesiosis can be useful if positive, but a negative result does not rule out the disease. Examining the red blood cells under a microscope may reveal the parasites, but few diagnostic laboratories are skilled at the tedious job of carefully observing the blood cells.

**Q. What is the treatment for babesiosis?**

A. It is important to remember that babesiosis is caused by a protozoan parasite and not by a bacterium, so antibiotics alone will not cure this disease. Many people appear to recover without treatment, but the disease may flare-up later. Since babesiosis is closely related to malaria, anti-malarial drugs are used to treat it. Usually an atovaquone drug like Mepron or Malarone is used along with an antibiotic such as azithromycin; the combination increases the effectiveness of the treatment. As with most tick-borne diseases, you do not develop any immunity after infection and you can get babesiosis over and over.

**Q. What are the symptoms of bartonella?**

A. Bartonella usually starts with a rash and swollen glands. Often it is a mild disease and the symptoms subside on their own. But in some cases, bartonella may cause on-going fatigue, mental symptoms, headaches, swollen glands, arthritis, generalized aches and pains similar to the other tick-borne diseases, seizures, neurological disorders, and even dementia. Vision loss and eye infections may occur. Symptoms tend to come and go.

Some areas have a very high rate of bartonella organisms in ticks, sometimes much higher than the rate for Lyme bacteria.

**Q. How is bartonella diagnosed?**

A. There are blood tests, but as with other tick-borne diseases, the tests are often inaccurate. Some doctors report success with a series of PCR tests, but tick-borne bartonella has not been recognized long enough to have other reliable diagnostic testing procedures. Few doctors are familiar with tick-borne bartonella. The cause of tick-borne bartonella is the same bacterium that causes “cat scratch disease,” which typically is far less serious and has different symptoms.

**Q. What is the treatment for bartonella?**

A. Antibiotics are used to treat bartonella. As with the other tick-borne diseases, treatment time can be lengthy. Since this disease has been recognized only recently, doctors are still learning which drugs are best.

**Q. What are the symptoms of Rocky Mountain spotted fever?**

A. Despite its name, Rocky Mountain spotted fever is far more prevalent in the South and East than it is in the Rocky Mountains. Like Lyme disease, it is caused by a bacterium. Untreated, it can sometimes be a fatal disease. It is spread by dog ticks as well as the deer tick. After two to fourteen days, most infected people suffer from a fever (sometimes 102°F or higher), headache, and achiness. Most people will develop a rash which may begin around the wrists and ankles, but it sometimes starts on the trunk. A classic symptom is a rash on the palms and soles of the feet, but fewer than half of the patients will have that. Untreated, half of the people infected with Rocky Mountain spotted fever will develop permanent neurological problems.

If you handle a tick while removing it, be sure to wash your hands thoroughly to minimize your risk of infection with RMSF. There are reports of infection simply from contact with an infected tick.

**Q. How is Rocky Mountain spotted fever diagnosed?**

A. Like Lyme disease, RMSF is a clinical diagnosis, which means that it is up to your doctor to evaluate your signs and symptoms to determine if you have the disease. Early blood tests are not accurate.

**Q. How is Rocky Mountain spotted fever treated?**

A. Doxycycline is the recommended antibiotic for RMSF.

**Q. Can children get Lyme disease and these other tick-borne diseases?**

A. Yes, and because they spend more time outdoors and may not know what areas to avoid, they are at greater risk than adults. Their symptoms may be different from an adult case of LD.

Children infected with LD often initially have a flu-like illness during the summer months and may sleep for a day or more. They often complain that light hurts their eyes. Few children develop the bull's eye rash. Stomach problems are common in children with LD.

With persistent LD, they tire easily and often do not want to participate in physical activity. Most devastating are the cognitive problems LD may bring. Infected children may suddenly develop learning disabilities and/or behavior problems. Researchers have found that LD is the cause of some instances of Attention Deficit Hyperactivity Disorder (ADHD). Some children become physically impaired or even disabled. Teenagers in particular may suddenly exhibit psychological problems. Many children of all ages struggle in school.

**Q. How are children treated for Lyme disease?**

A. Antibiotics are used to treat LD in children, but the drugs used may be different from those used to treat adults. Unfortunately, not many doctors are experienced in diagnosing and treating LD in children.

**Q. What about pregnant and nursing mothers?**

A. A woman with Lyme or other tick-borne diseases can transmit the infection to her baby before or after birth. The DNA of Lyme bacteria can be found in breast milk and it may be possible for the baby to be infected from nursing, although this has not been demonstrated in humans. Unfortunately, many antibiotics are unsafe for pregnant or nursing mothers, so a doctor's choice of treatment is limited. Expectant mothers need to be extremely careful to avoid becoming infected with tick-borne diseases. Early and aggressive antibiotic treatment of the mother during pregnancy appears to be effective in preventing infection of the newborn.

**Q. How do I prevent Lyme disease?**

A. The simple answer is to avoid being bitten by a tick. This isn't a very practical answer for many people who enjoy working and playing outdoors, and some occupations expose workers to ticks every day. Many Lyme sufferers were bitten in their own yard. But there are some things you can do to reduce your risk.

Ticks are most plentiful in areas where woodlands transition into fields, meadows, or yards. Ticks are often found in tall grass, gardens, or mulch beds. Deer paths through the woods are often loaded with ticks. Leaf litter, wood piles, and rock walls are also areas of high tick concentration. Where mice are present, ticks are usually abundant.

When you are in such areas, you need to be particularly vigilant to prevent a tick from attaching to your body. There are various insect repellents such as permethrin spray for clothing, that may help. Insect repel-

lents containing DEET are also effective. (On children, for safety, avoid products that contain more than 30% DEET.) Light-colored clothing makes it easier to spot ticks. Wearing long pants, long-sleeved shirts, and a hat are helpful. Tuck pant legs into socks to make it more difficult for ticks to crawl up your legs. Walk in the center of trails. After any time spent outdoors, check for ticks while you are out and as soon as you get back. Showering is also helpful. Remember that some of the ticks are extremely small and are almost impossible to see. Putting your clothing in a clothes dryer at high heat will kill ticks in about an hour.

There are products that can be used outdoors to kill ticks. For example, Damminix™ consists of cotton balls soaked in permethrin insecticide inside cardboard tubes that you place around your property where you expect mice may live (wood piles, stone walls, etc.). The cotton will be used by mice building their nests. The permethrin in the cotton kills the ticks on the mice with minimal danger to people, pets, or wildlife.

Some communities are experimenting with deer feeders that apply insecticide to the deer as they eat. Tick traps are also commercially available. Some lawn care companies can spray your yard with a version of permethrin.

Even if you rarely go outside, you can still be infected if your pets bring ticks into the house. Veterinarians recommend a product like Preventic™ collars, Frontline™, and Top Spot™ to minimize the risk. (Use of chemicals is a personal decision and we do not make product recommendations.)

Some researchers think that Lyme can be spread by other biting insects like mosquitoes, horseflies, deerflies, fleas, and lice. Although human infection has not yet been proven, these insects have been shown to carry the Lyme bacteria.

### **Q. What should I do if I am bitten by a tick?**

A. The tick should be removed promptly by pulling it slowly straight out with fine-pointed tweezers or a special tick-removal tool inserted as close to the skin as possible. Do not apply heat, alcohol, petroleum jelly, or any other substance. Aggravating the tick in this way may cause it to regurgitate into your blood, increasing your chances for infection. Do not squeeze the tick with your fingers either, as this can force Lyme bacteria into your body. You can use antiseptic on the site of the tick bite after the tick is removed.

Some experts believe that you can be infected almost immediately after

teria into your body. You can use antiseptic on the site of the tick bite after the tick is removed.

Some experts believe that you can be infected almost immediately after the tick attaches to your skin, while others think it takes 24 hours or more to be infected.

### **Q. What should I do after removing a tick?**

A. Call your doctor. Some doctors will prescribe several weeks of an antibiotic such as doxycycline as a preventive measure. If you develop symptoms after a tick bite, see your doctor and be sure to get adequately treated for LD and any co-infections you may have contracted.

You can save the tick in a plastic bag or small bottle and show it to your doctor so he can see what bit you. Ticks can be tested for a price, but treatment should not be delayed while waiting for results. A false-negative result could affect your doctor's decision to treat you.

### **Q. I think I have Lyme disease. How can I help my doctor in the diagnosis and treatment?**

A. First, keep careful track of your symptoms. Use the list in this booklet to check them off and take the list to your doctor. It's easy to forget to mention something important during an office visit. Make a copy of your list to leave with your doctor. Even if a symptom seems minor, you need to tell the doctor. He needs all the information to make a diagnosis. Charts to track your symptoms over time are available on our web site ([www.LymePa.org](http://www.LymePa.org)).

If your doctor seems skeptical of LD, you might want to bring some printed literature that may help him or her. Make sure that what you bring is from a credible source (such as a recognized medical journal), and present it tactfully. The Resource section in the back of this booklet will guide you to appropriate information.

Some doctors respond positively to patient input, but many do not. If you are not satisfied with the way you are being treated by your doctor, it may be time to find one better qualified to help you. Most patients with persistent LD have been to several doctors before getting a proper diagnosis and treatment.

Lyme Disease, perhaps more than most conditions, requires the active participation of the patient if good health is to be regained. Your efforts to educate yourself about LD will be well worth the time spent, and your doctor may learn as well.



**Q. How do I find a good doctor for Lyme Disease diagnosis and treatment?**

A. Ask at your local Lyme disease support group’s meeting, or ask a LD patient who seems to be well-informed. Doctors who treat LD generally prefer to maintain a low profile, since there is controversy surrounding this disease. The Lyme Disease Association maintains a nationwide doctor referral list at [www.lymediseaseassociation.org](http://www.lymediseaseassociation.org).

**Q. Why is there so much controversy regarding Lyme Disease?**

A. That’s one question that seems not to have a logical answer. There is a huge difference of opinion between some academic doctors and the doctors who actually treat Lyme patients. Some influential academic doctors have taken a position that LD is hard to catch and easily cured with a few days or weeks of oral antibiotics. They have advocated this position for a long time and they may be ignoring new research. The evidence is overwhelming that LD is a serious and potentially debilitating illness that can become a persistent, long-term disease. The cost of proper early treatment is far less than the expense that chronic LD-sufferers incur in their quest for relief.

**Symptoms**

In addition to Lyme, the co-infections of babesiosis, anaplasmosis/ehrlichiosis, bartonella, and Rocky Mountain spotted fever are prevalent in tick-endemic areas.

Here is a list of symptoms associated with Lyme and tick-borne co-infections. Many of these are symptoms of other diseases as well. An infected person may experience some or many of these symptoms, which is why diagnosis is often difficult. Check the boxes that apply to you. Remember that your doctor is looking for a *pattern* of symptoms.

A tick bite may go unnoticed, especially in the spring, when ticks are tiny. Not all cases of LD are caused by a tick bite. Some may result from placental transmission.

You may have symptoms now, or perhaps you had them in the past. Because LD symptoms often appear suddenly and tend to come and go, each symptom has two check boxes, labeled N and P, for “Now” and “Past.” Take this list with you when you see your doctor.

Even if you have many of these symptoms, it does not necessarily mean you have Lyme disease. Many Lyme symptoms are vague and overlap with many other diseases.

**N P (N = now, P = in the past)**

**Tick bite**

**Rash, often circular, usually spreading.** The “bull’s eye” rash occurs in fewer than 50% of Lyme patients. It may be centered on the tick bite and/or anywhere else on your body.

**Musculoskeletal System**

Joint pain or swelling

Joint stiffness, especially back or neck

Muscle pain or cramps

Creaking, popping, or cracking joints

Aches or burning in palms and/or soles of feet

Bone sensitivity, especially the spine

- Shin splints
- Foot pain (ankle, heel, plantar fasciitis)
- Gait disturbance
- Muscle weakness
- Sore soles (esp. in morning)
- Clumsiness
- Pain or swelling moves to different joints
- Backache (unexplained)
- Rib soreness
- Fibromyalgia (generalized muscle pain & tenderness)
- Tendonitis
- In babies, low muscle tone

### **Neurologic System**

- Headache — persistent/severe
- Headache — intermittent
- Headache — migraine-like
- Bell's Palsy (facial paralysis, usually one side only)
- Burning or stabbing pains, in odd, shifting places
- Sudden lightning-like jabs
- Tremors or unexplained shaking
- Numbness in parts of the body and/or extremities
- Tingling sensations (like an insect crawling on skin)
- Pinprick sensations
- Weakness or partial paralysis
- Pressure in the head
- Lightheadedness, wooziness, vertigo
- Fainting
- Twitching of muscles
- Poor balance, dizziness, difficulty walking, vertigo
- Increased motion sickness
- Warm/cool sensations at various locations
- Abnormalities of taste or smell
- Constant low body temperature (below 98.6°F)
- Seizure
- Abnormal blood flow in brain
- Diminished reflexes
- Hearing music or sounds others can't hear

- Visual or auditory hallucinations
- Odor hallucinations
- Restless legs syndrome (RLS)

### **Mental Capabilities**

- Memory loss (short or long term)
- Distorted memory
- Confusion, difficulty in thinking
- "Brain fog" (inability to concentrate; inattention)
- Declining performance in school or work
- Forgetting how to perform simple tasks
- Speech difficulty (slurred or slow and hesitating)
- Trouble finding the right word
- Drop in measurable IQ
- Dementia (Alzheimer's diagnosis)
- Dyslexia: letter, number, or word reversals
- Stammering, stuttering speech
- Going to the wrong place, disorientation
- Becoming lost in familiar places

### **Psychological well-being**

- Mood swings, irritability
- Easy frustration
- Unusual depression
- Crying impulses for no reason
- Over-emotional reactions, crying easily
- Panic, anxiety attacks
- Aggression, rage, road-rage
- Sleeping too much
- Difficulty falling or staying asleep (total insomnia)
- Napping during the day
- Ferocious nightmares
- Obsessive-compulsive behavior
- Suicidal thoughts
- Paranoia
- Disorientation (getting or feeling lost)
- Depersonalization (losing touch with reality, feeling "unreal")
- Bipolar disorder
- Other psychosis-like disorder

### **Head, Face, Neck**

- Stiff or painful neck
- Twitching of facial or other muscles
- Dental pain (unexplained)
- Painful teeth
- Painful gums
- Difficulty swallowing
- Hoarseness (unexplained)
- Drippy nose (unexplained)
- Pressure in head
- Cracks around sides of mouth
- Sore throat
- Scalp rash

### **Eyes, Vision**

- "Floaters"
- Double or blurry vision
- Pain in eyes
- Sensitivity to light
- Conjunctivitis
- Pressure in eyes
- Flashing lights
- Tearing eyes
- Dry eyes
- Vision loss/Blindness

### **Ears/Hearing**

- Decreased hearing in one or both ears
- Buzzing, clicking, or ringing in ears (tinnitus)
- Pain in ears with no medical cause
- Sensitivity to sound (hyperacusis)

### **Digestive and Excretory System**

- Diarrhea (unexplained)
- Constipation
- Abdominal pain, cramps
- Irritable bladder (trouble starting, stopping)
- Frequent need to urinate
- Upset stomach, nausea, vomiting
- Frequent heartburn

- Bloating
- Gastroesophageal reflux (acid reflux, GERD)
- Anorexia

### **Respiratory/Circulatory System**

- Shortness of breath, "air hunger"
- Persistent head congestion
- Chest pain (crushing sensation)
- Night sweats
- Unexplained chills
- Heart palpitations or extra beats
- Heart block on EKG
- Mitral valve prolapse
- Heart murmurs
- Elevated blood pressure
- Low blood pressure
- Vasculitis (inflamed blood vessels)
- Cough (non-productive, odd, unexplained)

### **Reproduction**

- Loss of sex drive
- Sexual dysfunction
- Unexplained menstrual pain, irregularity, flooding
- Unexplained breast or nipple pain, discharge
- Testicular or pelvic pain

### **General Well-being**

- Did you experience a flu-like illness, after which you have not felt completely well?
- Extreme, persistent fatigue
- Symptoms change, come and go
- Unexplained weight gain
- Unexplained weight loss
- Malaise
- Unexplained sweating
- Night sweats (drenching)
- Any type of rash
- Swollen glands
- Unexplained fevers (high or low grade)
- Itching

- Continual infections (sinus, kidney, yeast, bladder, etc.)
- Increased sensitivity to allergens
- Exaggerated response to alcohol
- In babies, failure to thrive
- In babies, delayed development

**Have you been diagnosed with:**

These disease have symptoms that overlap those of Lyme disease. Patients are sometimes misdiagnosed with these diseases when they may actually be suffering from Lyme.

- MS (multiple sclerosis)
- Parkinson's disease
- Gout
- Carpal Tunnel Syndrome
- Ménière's disease
- Hepatitis
- TMJ (jaw pain)
- Fibromyalgia
- Rheumatoid arthritis
- Lupus
- Chronic Fatigue Syndrome
- ALS (Lou Gehrig's disease)
- Crohn's disease
- Psychological/psychiatric symptoms
- ADHD (Attention Deficit Hyperactivity Disorder)
- Epstein-Barr virus infection
- Alzheimer's disease

**Notes for your doctor visit**

## References

The following print and on-line references are good sources to begin your quest for more information on Lyme disease. Unfortunately, World Wide Web addresses often change, or the pages are moved or deleted, so these URLs could be out of date by the time you look for the site. Entering “lyme disease” in any search engine (such as Google, Yahoo, etc.) will provide many sites to investigate.

This is a list of sites that seem to be reasonably stable and reliable. All contain many links to additional sites. These sites are a good starting point for your LD education.

[www.LymePa.org](http://www.LymePa.org) (links, general information and news for SE PA area)

[www.LymeDiseaseAssociation.org](http://www.LymeDiseaseAssociation.org) (general information and Lyme-literate doctor referrals)

[www.ilads.org](http://www.ilads.org) (the largest medical/professional organization devoted to tick-borne diseases; excellent guidelines)

[www.lymedisease.org](http://www.lymedisease.org) (links, general information and news for the California area)

[www.lymenet.org](http://www.lymenet.org) (general information, with many links, including support group listings)

[www.lymeinfo.net](http://www.lymeinfo.net) (general information)

[www.cdc.gov/ncidod/dvbid/lyme/index.htm](http://www.cdc.gov/ncidod/dvbid/lyme/index.htm) (the Centers for Disease Control and Prevention)

[www.fda.gov](http://www.fda.gov) (the Food and Drug Administration; search for “Lyme”)

[www.medscape.com](http://www.medscape.com) (This site requires a simple registration, but it is worth it to obtain excellent medical texts that you can give to your doctor if necessary. Search for “Lyme”)

[www.columbia-lyme.org](http://www.columbia-lyme.org) (LD research at Columbia University)

## Diagnostic Laboratories

These laboratories specialize in tick-borne diseases. Their web sites are also useful resources for testing information.

IGeneX, Inc. • 800-832-3200 • 797 San Antonio Road • Palo Alto, CA 94303 • [www.igenex.com](http://www.igenex.com)

Medical Diagnostic Laboratories • 877-269-0090 • 133 Gaither Drive Suite C • Mt. Laurel, NJ 08054 • [www.mdlab.com](http://www.mdlab.com)

## Books and Films about Lyme Disease

**Cure Unknown: Inside the Lyme Epidemic**, Pamela Weintraub, St. Martin's Press, 2008 (Excellent overview of the history and conflict, plus compelling personal stories.) [www.cureunknown.com](http://www.cureunknown.com)

**Under Our Skin: A Dramatic Tale of Microbes, Medicine & Money**, Open Eye Pictures 2008 (Award-winning documentary. DVDs available for purchase.) [www.underourskin.com](http://www.underourskin.com)

**The Widening Circle: A Lyme Disease Pioneer Tells Her Story**, Polly Murray, St. Martin's Press, 1996

**Coping with Lyme Disease**, Denise Lang with Joseph Territo, M.D., Henry Holt Company, 2004

**The Lyme Disease Solution**, Kenneth B. Singleton, M.D. (Practical information for Lyme patients, including nutritional suggestions.)

**Biography of a Germ**, Arno Karlen, Anchor Books, 2000 (The germ is *Borrelia burgdorferi*, the bacteria that causes Lyme disease.)

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The LDASEPA is an all-volunteer organization dedicated to improving the lives of people suffering from Lyme and other tick-borne diseases and preventing new cases through education, support, public information, research, and partnership with other organizations with common goals.

### **Public Meetings**

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LDASEPA meets on the third Wednesday of every month at the Kennett Friends Meetinghouse, PA Rt 82 one-half mile south of US Route 1, Kennett Square, PA.

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