

# What I Wish I Knew Before I was Diagnosed With Lyme Disease And Frequently-Asked Questions

By members of the Westchester Lyme Disease Support Group

1. If you discover it, save the tick! It strengthens your case that Lyme disease is a reasonable answer for your doctor to accept when symptoms appear.
2. Ask your doctor to base the diagnosis on clinical symptoms, not the blood test results. And urge him/her to prescribe the appropriate antibiotic for a minimum of 30 days at the first appearance of the suspicion of Lyme. The sooner you are correctly treated, the greater the chance of arresting the progress of the disease.
3. You can be bitten at ANY time of the year. If the temperature is 35°F, or above, the possibility of the ticks remaining active is as likely as it is in any other season.
4. Remember where you have been at the time you first became aware of symptoms striking you -- and as far back as several months earlier. Think carefully! Ever wider areas of the country are now considered endemic for tick presence, which indicates the greater likelihood for being bitten when outdoors.
5. Look to the habits of your pets as clues to the source of ticks indoors, and thus the risk to family members of being bitten.
6. In the Lower Hudson Valley region, the ratio of infected ticks to uninfected ticks is notably higher than in other areas of the country. Thus, if you are bitten, or begin to notice symptoms consistent with Lyme, recall this detail, and stress it when you speak with your physician.
7. There are many strains of the spirochete that are responsible for Lyme disease. Each causes its own peculiar, unique set of symptoms.
8. The disease does not confer immunity to its victims. *You can be re-infected repeatedly each time you are bitten.*
9. A two- or three-week course of antibiotic therapy is insufficient to insure that the spirochetes have been eradicated, or at the least brought under control. For an initial treatment, ask for a minimum of thirty (30) days of the appropriate antibiotic.
10. Symptoms may appear days, weeks, months or even years after the bite.
11. The dog vaccine does not protect your pet from contracting Lyme. It is not 100% effective; your veterinarian can verify this.
12. You will find conflicting opinions when the question arises: how rapidly is Lyme transmitted and symptoms begin to appear? A course of antibiotics at the earliest signs of infection, with justifiable risk of exposure to make such diagnosis plausible, can forestall much future suffering and aggravation of mild symptoms. The benefits far outweigh risks in this question.
13. One picture is worth a thousand words! If you are fortunate enough to develop a rash -- PHOTOGRAPH IT. It may later prove to be one of the most important pieces of proof you have to convince your doctor that it is Lyme disease causing your symptoms.

If you would like to add to this list, please write to us at: PO Box 82, Irvington-on-Hudson, New York 10533.

# PROTECT YOURSELF

## THINGS WE WISH WE HAD KNOWN ABOUT LYME DISEASE

protect yourself. Check yourself, family members and pets for ticks daily. Remember that ticks are carried by deer, mice, birds and other small animals found right in your own backyard. Nymphal ticks are the size of a poppy seed in early spring and are particularly hard to find. They are active above 35 degrees. You can be reinfected each time you are bitten.

**Remove** the tick properly, put it in a jar or baggie w/ moist towel and bring to your doctor and/or hospital to be sent for testing and the presence of the organism that causes Lyme disease. Since infection can spread rapidly throughout your system, you may want to consult your doctor about prophylactic treatment.

**Observe.** A person infected with Lyme disease can exhibit symptoms within days of exposure, but symptoms may appear weeks, months or even years after the bite.

**Treatable.** Lyme disease in its initial stage is often easily treatable; however, delayed diagnosis or inadequate treatment can lead to serious brain, heart or joint problems.

**Examine/evaluate.** Early symptoms can include headache, stiff neck, numbness, tingling, fatigue, swollen glands and migratory pains that may come and go. Late stage symptoms are generally multi-systemic and can be very serious.

**Co-Infection.** A single tick bite can transmit more than 1 tick-borne illness, such as babesiosis and/or ehrlichiosis. Co-infection can complicate Lyme diagnosis and treatment.

**Testing.** Since the diagnostic tests for Lyme are often inaccurate and therefore unreliable, a clinical diagnosis for Lyme disease should be made by a physician based on medical history and symptoms. The Centers for Disease Control and Prevention supports this in their literature pertaining to Lyme disease.

**Youngsters.** Children ages 2-12 are at the highest risk for being bitten. It is difficult, especially for children, to explain the subtleties of how they are feeling. Even if suffering, they may appear well and remain physically active.

**Obvious.** A person may have Lyme disease without presenting the most obvious and "classic" symptoms such as bull's eye rash, flu, joint pain or swelling. Many people never see a tick or develop a rash.

**Understand.** There are over 100 strains of Lyme disease in the United States; therefore, length and choice of antibiotic treatment vary greatly. Standard treatment of 2-3 weeks may be insufficient.

**Recurring.** Many people who suffer from Lyme disease experience symptoms that come and go over time. Continued symptoms or the development of new ones after treatment may be a sign of persistent infection. The medical community is divided over the existence of "chronic" Lyme.

**Symptoms.** The symptoms of Lyme disease, known as the Great Imitator, may mimic those of multiple sclerosis, lupus, chronic fatigue, fibromyalgia, mononucleosis, Alzheimers, Guillian-Barre Syndrome, ALS, rheumatoid arthritis, Parkinson's and ADD.

**Educate.** The effectiveness, longevity and safety of the Lyme vaccine is still in question and will not protect against other tick-borne illnesses.

**Lyme disease** can affect behavioral and cognitive functioning. Memory loss, attention deficit and processing problems, mental confusion, slurred speech, disorientation, irritability, depression, anxiety and learning problems have all been reported.

**Fact.** A person living in a Lyme endemic area should consider Lyme testing if suffering from a chronic condition that does not improve with treatment. Examples include recurrent gastrointestinal problems, chronic sore throats and chronic ear infections.

## Lyme Disease Symptoms

- Tick bite(deer tick or dog tick)
- Rash at bite site
- Rashes at other sites
- Unexplained fevers, sweats, chills
- Unexplained weight change(loss or gain)
- Fatigue, tiredness
- Unexplained hair loss
- Swollen glands
- Sore throat
- Testicular pain/pelvic pain
- Unexplained menstrual irregularity
- Unexplained milk production(lactation)
- Irritable bladder or bladder dysfunction
- Sexual dysfunction or loss of libido
- Upset stomach
- Change in bowel function(constipation, diarrhea)
- Chest pain or rib soreness
- Shortness of breath, cough
- heart palpitations, pulse skips, heart block
- Joint pain or swelling
- Stiffness of the joints, neck, or back
- Muscle pain or cramps
- Twitching of the face or other muscles
- Headache
- Neck creaks and cracks,neck stiffness
- Tingling, numbness, burning or stabbing sensations
- Facial paralysis(Bell's palsey)
- Eyes/vision: double, blurry, pain, increased floaters
- Ears/hearing: buzzing, ringing, ear pain
- Dizziness, poor balance, increased motion sickness
- Lightheadedness, wooziness, difficulty walking
- Tremor
- Confusion, difficulty in thinking
- Difficulty with concentration or reading
- Forgetfulness, poor short term memory
- Disorientation:Getting lost,going to wrong places
- Difficulty with speech
- Mood swings, irritability, depression
- Disturbed sleep: Too much, too little, early awakening
- Exaggerated symptoms or worse hangover from alcohol
- Heart murmur or valve prolapse
- Excessively itchy skin
- Hands and/or bottom of feet ache
- Transient muscle pain which jumps around the body