

# PORTRAITS OF LYME DISEASE

It isn't always easy to know who has or doesn't have Lyme disease. Lab tests are often unreliable and patients with Lyme disease don't have a certain "look". There are many individual features that vary from patient to patient and most are not highly distinctive. This means that doctors are looking for patient images that lack the sharp lines of a photograph and instead look more like a painting.

The articles in this section describe the "art" of making (or not making) a Lyme diagnosis. They discuss the specific elements doctors search for and consider when determining whether or not a patient has Lyme disease.

## A CLINICAL DIAGNOSIS

It is often said that Lyme disease is a clinical diagnosis; this is an important concept to understand. The term "clinical diagnosis" means that doctors decide whether or not a disease is present based on information obtained during patient visits and not on the basis of test results. Making a diagnosis on clinical grounds isn't unique to Lyme disease. Some diseases lack tests that reliably identify the ill. In others, the costs associated with testing – money, time, discomfort or the potential for harm – outweigh the potential benefits. In such situations, doctors are guided by history and exam findings to arrive at a diagnosis. Several common diagnoses are routinely made on clinical grounds, including tendonitis, angina, irritable bowel disease, migraines and ear infections.

Doctors weigh several factors in determining who has Lyme disease and who doesn't. The medical history is the key component of the diagnosis. Doctors are interested in knowing about:

- Exposure risks
- Tick bites
- Past and present illnesses
- Any family history of tick-borne diseases or illnesses that mimic Lyme diseases
- Presence or absence of Lyme-related symptoms and their time-line

In terms of the exam, findings compatible with Lyme disease are very important but so are findings that suggest diagnoses unrelated to tick-borne illnesses. Let's look at some of these elements in greater detail.

## TICK EXPOSURE AND BITES

In general, Lyme disease results from the bite of an infected blacklegged (deer) tick. People with no exposure to ticks have little risk of the disease while those with extensive exposure have a significant risk of acquiring the infection. Doctors may need to ask several questions to assess this risk.

Exposure can occur where people live, work or recreate. For example, according to Connecticut experts, it's estimated that three fourths of all cases of Lyme disease are picked up around the home.

(<http://www.ct.gov/caes/lib/caes/documents/publications/bulletins/b1010.pdf>)

Describing areas as being endemic or non-endemic has limited usefulness. Endemic areas are places where Lyme disease is known to exist and that information is important. Non-endemic often refers to counties, indicating that two or more cases have yet to be reported in those counties. However doctors and the public need to understand that being unreported is not the same as being absent.

Pets can increase their owners' risk of Lyme disease. That's because the animals may enter tick habitat, even when their owners don't, and bring ticks back to a shared space. Owners of cats that are allowed to roam outdoors are at higher risk than dog owners.

Not surprisingly, a history of a tick bite is highly significant, especially if it occurred in an area with lots of infected ticks.

A negative exposure history and lack of a known tick bite don't necessarily rule out Lyme disease. That's because many people are unaware that they live, work or spend their leisure time in a high-risk locale. Or, they know the risk associated with their usual activities but not new activities or locations (think vacations). Blacklegged ticks are incredibly small and their bites are painless, which is why most bites go unnoticed. In one study of patients with a Lyme disease rash, only 14% recalled the bite that caused their infection. (Berger BW. Dermatologic manifestations of Lyme disease. Rev Infect Dis 1989.)

## **ILLNESSES: YOURS AND YOUR FAMILY'S**

To properly evaluate a patient, doctors need to consider your current problems in the context of your medical history and that of your family members.

It could be that new symptoms are related to a change in a condition you're known to have or they could represent the return of a former medical problem. If either of these is true, then Lyme disease is less likely. Sometimes the medications you take for other illnesses cause side effects that make it seem like you're developing a new condition.

The medical histories of other family members may shed a lot of light on yours. That's because family members share many things – including genetics and possible exposure risks. Certain illnesses have a genetic basis and may run in families. Some of these diseases, like the auto-immune disorders, cause symptoms that are similar to the symptoms of Lyme disease. If a relative has one of these illnesses, your doctor will need to carefully consider this fact. Most doctors would want to rule-out that possibility before reaching a decision on Lyme disease.

The presence of any tick-borne illness in a close relative is also important information for your doctor to have because family members often share the same exposure risks. They often live in close proximity to each other, vacation together, and may even work in the same location. Many families have a shared hobby or favorite leisure activity that exposes all members to ticks and the diseases they carry.

# LYME DISEASE SYMPTOMS

The symptoms are the most important elements of a Lyme disease evaluation.

Patients with Lyme disease often have multiple symptoms involving many different areas or systems of the body. This makes sense because *Borrelia burgdorferi*, the bacterial cause of Lyme disease can go anywhere in the body. In fact, unless the illness is limited to an erythema migrans rash or a swollen joint, it's expected that most patients with Lyme disease will have numerous symptoms spread across many body areas or systems.

## Lyme Disease Symptom Checklist

The checklist posted here contains many frequently reported symptoms and is similar to other commonly used lists. Please note that being absent from the list doesn't mean that a symptom isn't Lyme-related; it just isn't practical to try to list each and every one. Because many doctors are unaware of the breadth of Lyme disease symptoms or may not associate a particular symptom with Lyme disease, the pdf of this list includes references to the medical literature, verifying that symptoms on the checklist may be Lyme-related.

### GENERAL

- Fever
- Night sweats
- Fatigue, lack of endurance
- Unexplained weight gain/loss
- Generalized, unprovoked pain
- Migratory pain

### HEAD, FACE, NECK

- Headache, mild or severe
- Facial flushing
- Pressure in head
- Jaw pain or stiffness
- Unexplained hair loss
- Dental problems/pain (unexplained)
- Twitching of facial muscles
- Stiff or painful neck
- Facial paralysis (Bell's palsy)
- Sore throat, hoarseness
- Tingling of nose, tongue, cheek

### EYES/VISION AND EARS/HEARING

- Double or blurry vision
- Difficulty with night vision
- Increased floating spots
- Pain in eyes, or swelling around eyes
- Oversensitivity to light
- Flashing lights/Peripheral waves/phantom images
- Change in color vision
- Decreased hearing in one or both ears
- Buzzing or ringing in one or both ears
- Pain in ears, oversensitivity to sounds
- Auditory hallucinations

### GASTROINTESTINAL AND GENITO-URINARY SYSTEMS

- Upset stomach (nausea/pain)/ heartburn
- Recurrent vomiting
- Diarrhea/constipation
- History of irritable bowel disease

- Irritable bladder or interstitial cystitis
- Testicular or pelvic pain
- Decreased libido
- Unexplained menstrual irregularity
- Unexplained milk production

### **MUSCULOSKELETAL SYSTEM**

- Bone pain, joint pain or swelling
- Carpal tunnel syndrome
- Stiffness of joints, back, neck
- Frequent tendonitis, tennis elbow
- Muscle pain or cramps, muscle spasms
- Sore soles

### **RESPIRATORY AND CIRCULATORY SYSTEMS**

- Shortness of breath, cough
- Swelling of feet
- Trouble breathing when lying down or need to prop self up with pillows
- Chest pain or rib soreness
- Peripheral vascular abnormalities
- Rhythm disturbances- extra beats, slow heart rate, palpitations

### **NERVOUS SYSTEM**

- Burning, stabbing, aching or shock sensations
- Lightheadedness, fainting
- Numbness, tingling, pinpricks
- Increased motion sickness
- Problems with peripheral nerves
- Abnormalities of vision, hearing, smell, taste or touch
- Muscle weakness
- Muscle atrophy or partial paralysis

- Muscle twitching
- Speech difficulty (slurred or slow)
- Poor balance
- Dizziness
- Difficulty walking, gait problems
- Tremors
- Seizures
- Sleep problems – excessive sleep, insomnia, sleep apnea, narcolepsy, unusual sleep behaviors

### **COGNITIVE**

- Memory loss (short or long term)
- Confusion, difficulty in thinking
- Difficulty with concentration or reading
- Stammering speech
- Word searching, misspeaking
- Disorientation (getting or feeling lost)
- Going to the wrong place
- Forgetting how to do simple tasks (examples: tying shoes, opening locks, operating home appliances)
- History of dementia

### **NEUROPSYCHIATRIC**

- Mood swings, irritability
- Feeling as if you are losing your mind
- Over-emotional reactions, crying easily
- Depression
- Bi-polar disorder
- Panic attacks, anxiety
- Obsessive-compulsive disorder
- Psychosis



This information is courtesy of Partnership for Healing and Health, Ltd. It is intended for educational purposes only and not to replace or supersede patient care by a healthcare provider. If you suspect you have a tick-borne illness, consult a healthcare provider familiar with the diagnosis and treatment of tick-borne diseases.

PHH offers evidence-based education and programs on Lyme disease and other tick-borne illnesses for the general public and health care professionals.  
For information, contact [md@phhmd.com](mailto:md@phhmd.com)