

Symptoms of Lyme

Without reliable lab tests, clinical symptoms remain the most relevant indicators of Lyme

Lyme disease may present with a variety of symptoms. In its early stage, the illness might seem like the flu — fever, chills,



sweats, muscle aches, fatigue, and/or nausea; some may experience joint pain. Some may experience a rash or a facial drooping called Bell's palsy. But while a rash shaped like a bull's-eye is considered characteristic of the disease, many Lyme patients develop a different kind of rash or none at all.

Estimates of patients who develop a rash vary widely, ranging from about 30% to 80%. For example, a CDC report on Lyme carditis, which can be fatal, found that only 42% of cases had a rash.

If Lyme disease is not diagnosed and treated early, the infection may persist and become chronic, referred to as late-stage or post-treatment Lyme disease (PTLD). Chronic Lyme disease (CLD) can also develop when early treatment is inadequate.

While some symptoms of chronic or late stage Lyme disease are similar to those of early Lyme, there are important differences. Fatigue is a prominent feature in both groups. The erythema migrans rash, fever, sweats, and chills occur in 60% of patients with early Lyme while people with chronic Lyme are more likely to suffer from neurologic complications like cognitive difficulty, neuropathy, and depression (>60%).

lymedisease.org's 2014 patient survey compared the severity of CLD to other chronic conditions.¹ Since Lyme disease can spread to any part of the body, it typically affects more than one body system — brain and nervous system, muscles and joints, heart and circulation, digestive tract, and so on. Based on responses from over 5,000 patients, the survey assessed the health-related quality of life of patients with CLD. Those surveyed reported an average of three severe or very severe symptoms, with 74% reporting at least one symptom as severe or very severe.

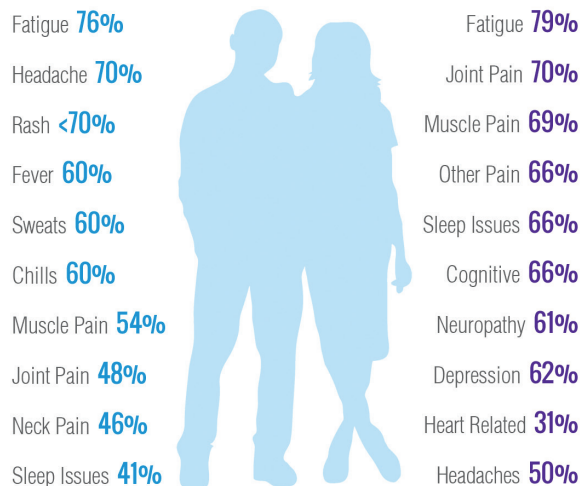
1 Johnson L, Wilcox S, Mankoff J, Stricker RB. (2014), Severity of chronic Lyme disease compared to other chronic conditions: a quality of life survey. *PeerJ* 2:e322.

The authors of the LDo study conclude that “the heavy burden of illness associated with CLD highlights the need for earlier diagnosis and innovative treatment approaches [to] reduce the burden of illness and concomitant costs.”²

In 2008 Joseph Burrascano, MD, a pioneer in treating CLD, published an extensive checklist of symptoms along with the 16th edition of his handbook, *Diagnostic Hints and Treatment Guidelines*. That checklist remains helpful to patients and practitioners to this day (visit lymedisease.org). Sam Donta, MD, identified similar symptoms in his study of pediatric patients.³ Many children with Lyme also develop behavioral changes, school phobias, academic problems, and learning disabilities. Many Lyme symptoms (such as fatigue, cognitive impairment, joint pain, poor sleep, mood problems, muscle pain, and neurological presentations) also occur in other diseases. Symptoms of Lyme significantly overlap those of chronic fatigue, fibromyalgia, rheumatoid arthritis, multiple sclerosis, Parkinson's, ALS, depression and Alzheimer's. Many Lyme patients report being misdiagnosed with a different condition before being properly diagnosed with Lyme.

LYME DISEASE SYMPTOMS

EARLY LYME* -vs- CHRONIC LYME**



* (Aucott 2013) ** (Johnson 2014. Moderate to very severe symptoms)
Estimates of rash rates range from 25-80% <http://tinyurl.com/kfvu8yt>

Counting cases

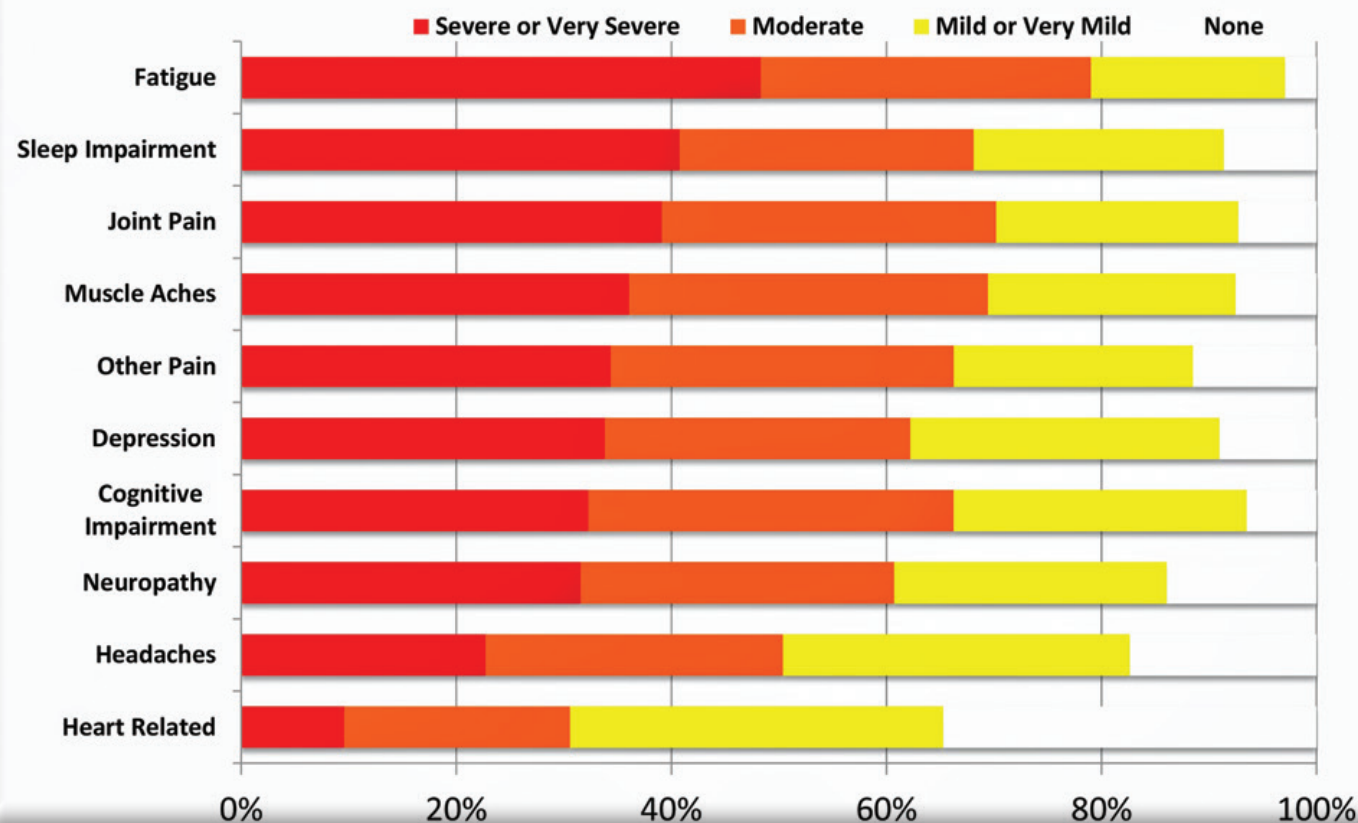
The Centers for Disease Control (CDC) count only Lyme cases meeting the agency's strict surveillance criteria. This requires two positive blood tests — a screening test, ELISA, followed by a confirmatory Western blot — as well as other “objective”

2 Ibid., study published in *PeerJ* is available online at <http://bit.ly/18lrh8R>.

3 The 2012 Donta study published in *Open Neurology Journal* is available online at <http://1.usa.gov/1GuNXi2>.

Symptom Severity

75% of chronic Lyme patients experience severe or very severe symptoms. 63% describe two or more symptoms as severe or very severe.



Johnson, L., Wilcox, S., Mankoff, J. and Stricker, RB (2014) Severity of Chronic Lyme Disease Compared to Other Chronic Conditions: A Quality of Life Survey. PeerJ, DOI 10.7717/peerj.322. <https://peerj.com/articles/322/>

indications of Lyme, such as Bell's palsy or joint swelling. Unfortunately available diagnostic tests are notoriously unreliable, and the "objective" symptoms considered definitive of Lyme by the CDC are not common. The chart above reflects the breakdown of symptoms manifested by patients whose confirmed cases were reviewed by the CDC from 2001 to 2010.⁴

The poor performance of diagnostic tests contributes to what many experts view as severe undercounting of Lyme cases by the CDC. In 2013 the CDC increased its estimate of the annual incidence of Lyme disease from 30,000 to 300,000 cases, based on its analysis of insurance claims, lab

reports and a public survey.⁵ Many believe that these revised estimates are still too low.

Co-infections

Since *Borrelia burgdorferi* was first identified in 1981, researchers have identified more than 15 tick-borne pathogens. Ticks can carry and transmit many different diseases at the same time. Co-infections are common among those with CLD. Generally a person with one or more co-infections experiences a more severe illness, more symptoms, and a longer recovery. The CDC recommends that physicians consider possible co-infections when patients experience severe symptoms.

⁴ The CDC study is available online at <http://1.usa.gov/1FsQ6JY>.

⁵ The CDC study published in JAMA (2013) is available online at <http://bit.ly/1woum2V>.

Comparing Apples to Apples

The 2014 LDo patient survey is the first to utilize a broad health-related quality of life (HRQoL) metric to study chronic Lyme disease (CLD). HRQoL is used in numerous government population surveys to assess health in the general population, determine the symptom burden of chronic diseases, identify health disparities and unmet health needs, evaluate progress on achieving goals, and inform public health policy. It permits the burdens of different diseases to be compared despite the widely varying time course, symptom patterns, functional impairment, and clinical severity associated with these diseases. The patient-centered HRQoL indicators are considered robust predictors of subsequent health outcomes and health system utilization.