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Patient information

Post treatment Lyme disease syndrome

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What is Lyme Disease?

Lyme disease is a bacterial infection spread to humans when they are bitten by an infected tick. In the vast majority of cases, it is successfully treated with oral antibiotics.

Lyme disease occurs in several forested temperate regions worldwide including the UK, north-western, central and eastern Europe, USA and Asia. Risk for travellers is very low except for visits to rural areas. Hikers and campers are at higher risk. Many mammals can be infected and deer act as an important reservoir. The disease is most common in summer months.

Course of Disease

The period between exposure to an infection and the appearance of the first symptoms is usually 3 to 10 days. Many people with early-stage Lyme disease develop a distinctive circular rash at the site of the tick bite. The affected area of skin will be red and the edges may feel slightly raised. Some people also have flu-like symptoms in the early stages, such as fever, chills, headaches, and muscle and joint pain. Involvement of the central nervous system including the brain may follow. Central nervous systems and other complications, including changes in heart rhythm may occur weeks or months after the onset of untreated illness. Arthritis may develop two years after onset.

How is Lyme disease treated?

Treatment with an antibiotic is successful in the majority of patients with each of the stages of Lyme disease. Most people with early disease have complete resolution of the symptoms and signs of infection within 20 days. A short three week course of oral antibiotics such as doxycycline or amoxicillin is the cure. In more complicated cases Lyme disease can usually be successfully treated with four-six weeks of antibiotic therapy. The response to therapy is often slower in patients with complicated disease, particularly in those presenting with paralysis.

Does treatment failure occur?

Antibiotic treatment failure does occur, but is rare. There have been no documented cases of Doxycycline (antibiotic) resistant *B. burgdorferi* (Lyme Disease) after the recommended antibiotics used in therapy. Treatment failure usually happens because of poor absorption or non-compliance with treatment.

When the term "treatment failure" is used, it usually refers to symptoms that have persisted or recurred.

What is "Post Treatment Lyme Disease Syndrome (PTLDS)"

In some patients with Lyme Disease, symptoms such as tiredness

Has anyone looked at the potential benefits of long-term antibiotic therapy on PTLDS

Yes, the American National Institute of Allergy and Infectious Diseases conducted three randomised-controlled clinical trials studying the effectiveness of prolonged antibiotic therapy for treating PTLDS. The study provided evidence that patients reporting PTLDS symptoms had severe impairment in overall physical health and quality of life. However, results showed no benefit from prolonged antibiotic therapy when compared with dummy pills (placebos) in treating those symptoms.

In 2016, a clinical trial conducted in the Netherlands also concluded that, in patients with persistent symptoms attributed to Lyme disease, longer term treatment with antibiotics did not provide additional benefits compared with shorter treatment.

and joint and muscle aches persist even after treatment, a condition termed “Post Treatment Lyme Disease Syndrome (PTLDS)”.

The term “chronic Lyme disease” (CLD) has been used to describe people with different illnesses. While CLD is sometimes used to describe illness in patients with Lyme disease, it has also been used to describe symptoms in people who have no clinical or diagnostic evidence of a current or past infection with Lyme Disease. *Because of the confusion in how the term CLD is employed, and the lack of a clearly defined clinical definition, the term ‘chronic Lyme disease’ is not used.*

In patients who have symptoms after being treated for Lyme disease and who have no evidence of active infection (patients with PTLDS), studies have shown that more antibiotic therapy is not helpful and can be dangerous.

If long-term antibiotic therapy is not effective why do some people report improved symptoms following such treatment?

Carefully designed studies, using dummy pills/placebos, have failed to demonstrate that prolonged antibiotic therapy is beneficial. Although isolated success stories are always good to hear, such reports alone are not sufficient grounds to support prescribing patients' long courses of antibiotics.

The following observations may address the issue of persistent symptoms:

There are several reasons for lack of response to standard antibiotic therapy. These include:

- The initial diagnosis of Lyme disease was incorrect.
- Patients with early Lyme disease may be co-infected with another infection transmitted by ticks.
- It is possible to have both Lyme disease that has been cured and another condition that persists. Examples include fibromyalgia, depression, patellofemoral joint disease, or another disease not related to Lyme.
- The knee involvement with Lyme disease may persist for months after antibiotic therapy.

In conclusion there is a lack of benefit from additional antibiotics —and PTLDS symptoms are difficult to treat. Numerous trials of repeat antibiotic therapy determined that it provides no benefit and carries significant risk.

References and useful links please refer to:

- <https://www.niaid.nih.gov/diseases-conditions/chronic-lyme-disease>
- <https://bestpractice.bmj.com/topics/en-gb/224>
- <https://www.nhs.uk/conditions/lyme-disease/>
- <https://www.nice.org.uk/guidance/ng95/informationforpublic>