

What is the incidence of Lyme disease in the UK?

This disease was known in Europe by the early 20th century. The first confirmed UK case was in 1985¹⁶ and it is becoming more common¹⁷. In 2024 there were about 2000 laboratory-confirmed cases in the UK. The UK Health Security Agency acknowledges that, as clinical diagnoses are not included, the true number of new cases is unknown. Given the difficulties of diagnosis and that full recovery may not take place in some cases, the total number of people affected may be growing.

Are there other tick-borne infections?

Several other infections may be carried by UK ticks. These are currently far less common than Lyme disease¹⁸⁻²⁰ and rarely diagnosed in the UK. The main ones are -

Anaplasmosis tends to cause more fever than Lyme disease and give rise to abnormal liver function tests and low white blood cells and platelets.

Babesiosis infects red blood cells and can cause anaemia, dark urine and flu-like symptoms. Those with weak immune systems are more at risk.

Borrelia miyamotoi causes a Lyme-like illness but without an EM rash and with fluctuating fever and headache.

Rickettsiosis can cause a spotty rash, fever and sometimes a black "eschar", or scab, at the site of the tick bite.

Louping Ill Virus is endemic to UK upland areas and causes a severe central nervous system infection. It is common in sheep, grouse and other animals. Human cases are very rare.

Tick-Borne Encephalitis Virus has recently been diagnosed in a handful of UK cases. Causes a few days of flu-like symptoms, a gap of some days, then possibly meningitis. Endemic in Europe and Asia. A vaccine is available²¹.

All these except Louping Ill are more common in mainland Europe. North America has a different spectrum of tick-borne diseases.

Alpha-Gal Syndrome is not an infection; it is a delayed allergy to red meat caused by a reaction to tick saliva.

Can Lyme disease be prevented?

There is no vaccine available yet. However, there are many measures you can take to protect yourself. Be aware of the risk, avoid risky areas if possible and check your skin for ticks.

It is essential to know how to remove a tick properly if it is attached to your skin, and to seek prompt medical advice if you experience any symptoms. See LDA website for tick removal tools and advice.

Further information

You can contact us for feedback on our leaflets or references for the information provided - see our website. All our leaflets can be downloaded from our website where you can find out more about ticks and Lyme disease.

www.LymeDiseaseAction.org.uk

You can write to us at:

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61, Bridge Street,
Kington
HR5 3DJ UK



Including a donation will help us in our work for people affected by Lyme disease.

Please don't bin this leaflet - pass it on.

Disclaimer: Lyme Disease Action publications are not a substitute for professional medical advice and are intended as general information only. If you have or suspect you may have Lyme disease you should consult a doctor.

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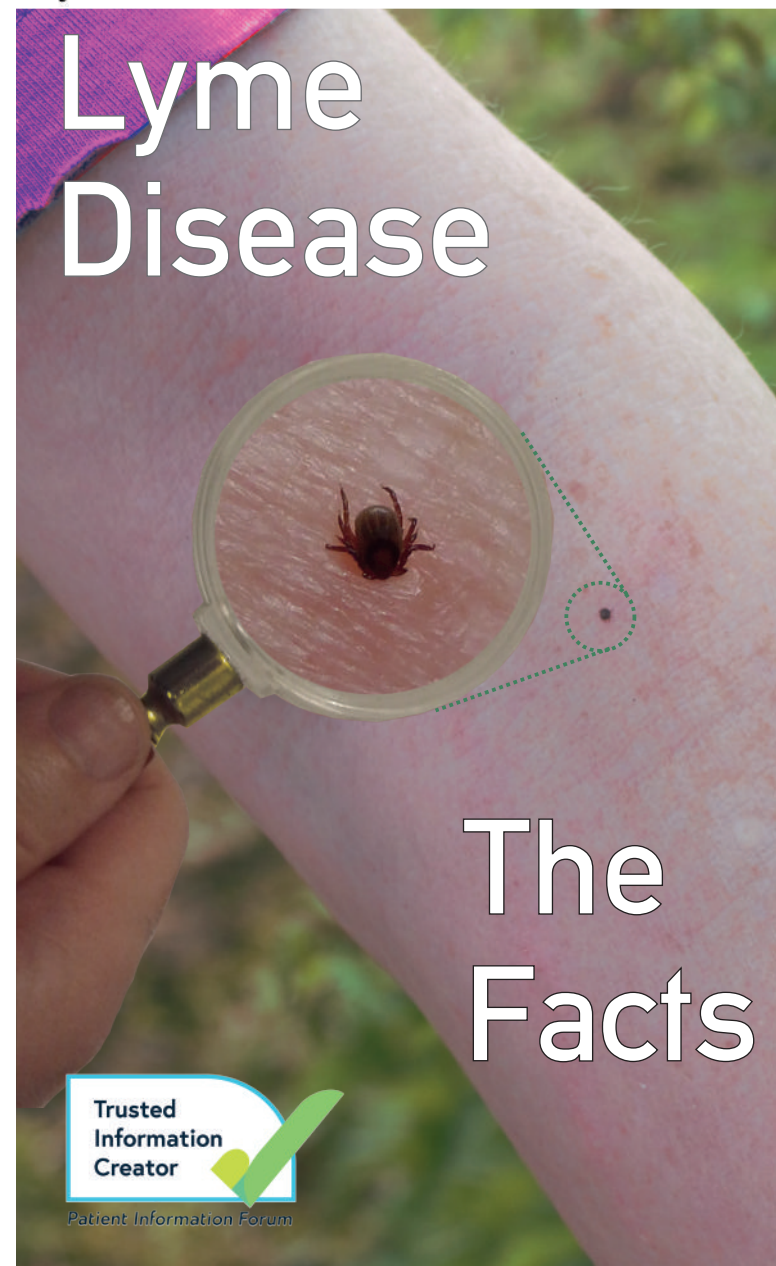


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Lyme Disease Action

Lyme Disease



Patient Information Forum

What is Lyme disease?

Lyme disease, also known as Lyme borreliosis, is an infectious disease caused by the bacterium *Borrelia burgdorferi*. It is the most common tick-borne disease in Europe¹.

There are many species of *Borrelia* bacteria worldwide but not all cause disease. At least three species are currently known to cause disease in the UK. They are *Borrelia afzelii*, *Borrelia garinii* and *Borrelia burgdorferi sensu stricto*. They all cause a broadly similar disease, but slightly different presentations, e.g. *B. garinii* gives more neurological symptoms and *B. burgdorferi* more arthritis². *B. miyamotoi*, more closely related to tropical relapsing fevers, is also present in UK ticks³ and causes a Lyme-like illness with some key differences (see over).

How do you catch Lyme disease?

Bacteria are passed when an infected tick attaches to your skin. Ticks may be very small and attach painlessly, so may go unnoticed until itching develops several hours later. The risk of infection is greater the longer a tick remains attached⁶. They tend to attach to the legs of adults, but often to the head or neck of children. Most UK ticks do not carry the infection: in any one place between zero and about 1 in 5 of the ticks which bite humans have been found to be infected⁴. This varies from year to year⁵.

Where can you catch Lyme disease?

In the UK, Lyme disease is carried by the sheep tick, *Ixodes ricinus*, the hedgehog tick, *Ixodes hexagonus* and some others⁷. These ticks feed on wild mammals and birds from which they pick up the bacteria, passing it on to humans and some domestic animals. Ticks can be found across the UK in woods, fields, moorland and heath, and also in town parks and gardens: anywhere where there is wildlife to feed on and vegetation to protect them from drying out.

How does Lyme disease start?

If the tick has passed bacteria, your immune system will try to kill them. If bacteria survive and start an infection, symptoms may appear on average about 2 weeks after the tick bite.

What are the symptoms of Lyme disease?

Lyme disease can affect any part of the body and cause many different symptoms. Common early symptoms can be 'flu-like (aching, fever and headache), extreme fatigue, stiff neck, facial palsy, joint and muscle pain and skin sensations such as tingling, burning and numbness.

In many cases the first symptom is a characteristic spreading, non-itchy 'bull's eye' rash 5-30cm across. This rash is called erythema migrans or EM. UK figures suggest about 1 in 3 people don't see the rash⁸.

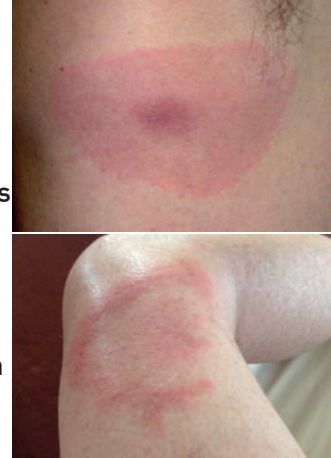
Symptoms vary from person to person. Children particularly may present with a slow onset meningitis.

Other symptoms known to be caused by Lyme disease are many and diverse, and can vary from mild to severe. They include disturbed sleep, muscle pain & weakness, nerve pain, heart palpitations and sensitivity to light & sound. Nervous system complications may begin early in the first few weeks and months and this is known as Lyme neuroborreliosis - see our separate leaflet.

Is there a test for Lyme disease?

Several laboratory tests aim to confirm diagnosis. The most common blood tests (serology) detect selected antibodies to the bacteria.

Negative blood tests can occur if testing is too early (not enough antibodies developed) and in people given inadequate early treatment with antibiotics or immunosuppressive drugs^{9,10} (antibody production affected). There is some evidence that before treatment antibody levels fluctuate¹¹ and that they go down in long standing infection¹². In cured patients antibodies do go down, but they can last for months or years.



Erythema migrans rashes

What is the treatment for Lyme disease?

Treatment is with antibiotics and is very effective if started early. If an EM rash occurs, treatment should be started immediately without waiting for blood test results, which at this stage are likely to be negative.

For Lyme disease diagnosed at a later stage the best treatment is uncertain. See the NICE Guideline for treatment recommendations.

What happens during treatment?

Some people feel a worsening of symptoms early in treatment called a Jarisch-Herxheimer reaction. If this happens a doctor should be consulted to check for an allergy to the antibiotic. Patients should be aware that the most common antibiotic used, doxycycline, can cause sun sensitivity and stomach irritation.

Most people treated early will feel better quickly, but it is important to complete the course of treatment.

After Treatment

In some, recovery may be gradual in the following months. If patients get worse after treatment has finished they should consult their doctor in case re-treatment is necessary as the NICE guideline suggests. There are documented cases of relapse.

Even after recommended treatment a small number of people carry on having symptoms. Called Post Treatment Lyme Disease Syndrome (PTLDS), we do not know what causes this. Research has started to look for whether this could be due to an immune system reaction, tissue damage or active Lyme disease. There is no test that can tell the difference between PTLDS and active Lyme disease because antibodies can last for years even in someone with no remaining symptoms.

How do I know if I've got Lyme disease?

Lyme disease may not be an easy diagnosis for the doctor to make, especially if the patient had no rash and does not recall a tick bite. If a patient remembers a tick bite and then becomes unwell, Lyme disease should be considered and clinical judgement used.