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 1985[16] and it is becoming more common[17]. In 2018 there were about 2000 laboratory-confirmed cases in the UK. Public Health England & Health Protection Scotland acknowledge 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. If present they may complicate diagnosis and recovery. The prevalence of these infections in UK ticks is not fully documented but they are currently far less common than Lyme disease[18-20]. 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 and red discolouration of urine as well as significant headache, breathlessness and fatigue.

Rickettsiosis can cause a spotty rash, fevers and sometimes a black "eschar", or scab, at the site of the tick bite. No documented cases yet in the UK.

Borrelia miyamotoi causes a Lyme-like illness but without an EM rash and with more fever (sometimes coming and going) and headache.

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

Tick-Borne Encephalitis Virus was found in a few UK ticks in 2019. Causes a few days of flu-like symptoms, a gap of some days, then possibly meningitis. Endemic in much of Europe and Asia. A vaccine is available[21].

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

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

References used can be downloaded from the leaflets page of the 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:

Lyme Disease Action,
61, Bridge Street,
Kington
HR5 3DJ UK

You can also contact us for feedback on our leaflets.

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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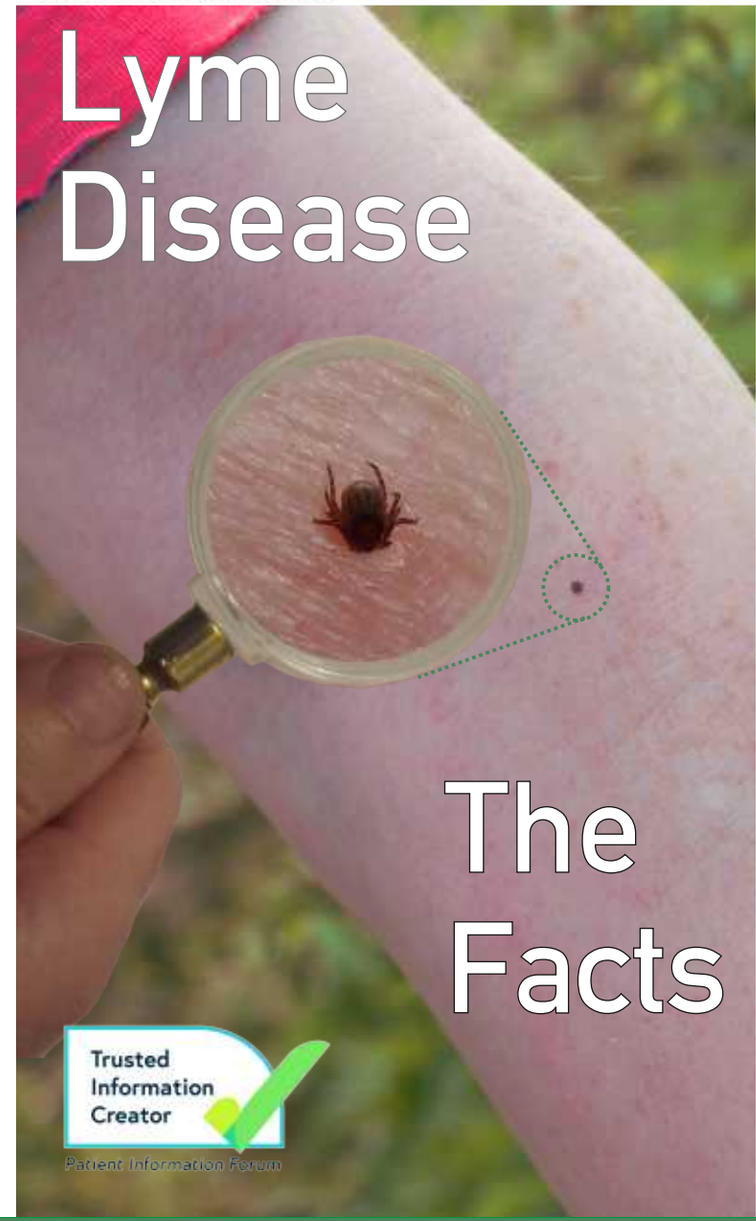

Lyme Disease

The Facts

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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 Europe[1].

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 arthritis[2]. *B. miyamotoi*, more closely related to tropical relapsing fevers, is also present in UK ticks[3] and causes a Lyme-like illness with some key differences (see over).

How do you catch Lyme disease?

Bacteria are transmitted to humans by the bite of an infected tick. Most UK ticks do not carry the infection: in any one place between zero and about 20% of the ticks which bite humans have been found to be infected[4] and this varies from year to year[5]. The risk of infection is greater the longer the tick remains attached[6]. Tick bites are usually painless, so may easily go unnoticed.Ticks may be very small. They tend to attach to the legs of adults, but often on the head or neck of children.

Where can you catch Lyme disease?

In the UK, Lyme disease is carried by the sheep tick, *Ixodes ricinus*, the hedgehog tick, *I. hexagonus* and some others[7]. 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 urban 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 bacteria have been transmitted, symptoms may appear on average about 2 weeks after the tick bite. Lyme disease can be latent and active infection can be triggered later by other factors such as stress and other diseases.

What are the symptoms of Lyme disease?

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

In some cases the first symptom may be a characteristic, spreading 'bull's eye' rash 5-30cm across. This rash is called erythema migrans or EM. UK figures suggest around 1 in 3 cases do not see the rash[8].

Erythema migrans rashes

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

Other symptoms known to be associated with Lyme disease are many and diverse, and can vary from mild to severe. They include disturbed sleep pattern, muscle pain & weakness, nerve root pain, 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) aim to detect selected antibodies to the bacteria. However, no test can reliably exclude Lyme disease.

Negative blood tests can occur if testing is too early and in people given inadequate early treatment with antibiotics or immunosuppressive drugs[9,10]. There is also some evidence that antibody levels fluctuate[11] and that they decline in long standing infection[12] but more research is needed.

What is the treatment for Lyme disease?

Treatment is with antibiotics and is highly 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. See NICE Guideline NG95 2018.

For Lyme disease diagnosed at a later stage the optimum treatment is not known. There are insufficient quality European treatment trials longer than 28 days, and the failure rate of trials of conventional 10-28 day treatments ranges from 0% to 60%[13]. There are documented cases of relapse[14].

What happens during treatment?

A worsening of symptoms called a Jarisch-Herxheimer reaction may complicate treatment. This does not occur in every case but if it does further medical advice should be sought. Patients should be aware that the most common antibiotic used, doxycycline, can cause sun sensitivity and stomach irritation.

Some people, especially those treated early, start to feel better very quickly, but it is important to complete the course of treatment. In some, recovery may happen slowly in the months following treatment. If patients get worse after treatment has finished they should consult their doctor in case re-treatment is necessary as the NICE guideline suggests.

Other medicines may also have a place in treatment for relief of symptoms such as pain. There is some evidence that probiotics ("good" bacteria in capsules) can help prevent antibiotic associated diarrhoea[15].

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

Lyme disease may not be an easy diagnosis for the doctor to make. This is especially so 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. After all investigations have been done, clinical judgement may be used to make a diagnosis.