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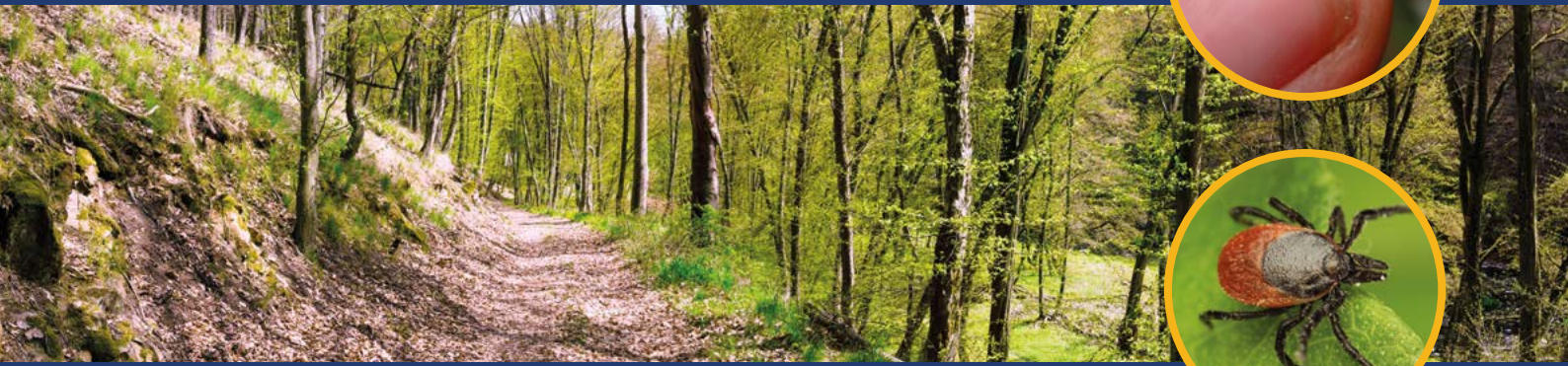
LYME RESOURCE CENTRE



Lyme Disease - What Health Professionals Need to Know

Lyme Resource Centre is a charity with a mission to minimise risk of Lyme disease whilst enjoying the outdoors, by educating the public and healthcare professionals about ticks and Lyme disease.

www.lymeresourcecentre.com

Registered SCIO Charity - SC049151

Contents

Introduction

Lyme disease is a complex and increasingly common condition across the UK, with early symptoms that can resemble many other presentations seen in primary care. Timely recognition and treatment are essential to prevent potentially serious long-term complications.

GPs and primary care teams have a critical role to play in early detection, accurate diagnosis, and prompt treatment of Lyme disease.

This resource offers a concise, evidence-based overview of Lyme disease — covering its epidemiology, clinical features, diagnostic approach, and treatment guidelines. It also includes practical advice on tick bite prevention and management.

This material is intended to support reflective learning, enhance team discussions, and strengthen confidence in managing Lyme disease in primary care.

Key Facts

- Lyme disease (LD) is a bacterial infection caused by the spirochete *Borrelia burgdorferi*, transmitted to humans via the bite of an infected tick.
- It is the most common tick-borne disease in the UK and is increasing in incidence.
- Ticks are found throughout the UK in rural areas as well as urban parks, gardens; they are carried and feed on mammals and birds.
- Ticks can be very small so easily go unnoticed; bites are usually painless.
- Prompt, correct tick removal reduces the risk of infection; there is no proven minimum attachment time for transmission of infection.
- Early diagnosis & antibiotic treatment as per NICE guideline 95 - Lyme disease, gives best chance of cure.
- An **erythema migrans** rash (EM) is diagnostic of LD. The rash is not necessarily a 'bull's eye', absent in 30% of cases and easily misdiagnosed. Serology is not required.
- Early LD symptoms may be flu-like and non-specific (with or without EM rash).
- Symptoms in early or late disseminate LD may be multisystemic and mimic other conditions.
- Lyme serology may be unreliable at any stage; a negative test does not exclude diagnosis.
- 10-20 % of patients report significant ongoing symptoms after standard treatment.
- There is no international consensus on duration of treatment or the cause, management of persistent symptoms.

Scan for more
"Key Facts For Health Professionals"

CDC ID 1669 Michael L. Levin, PhD - photo credit Jim Gathany

About Ticks

Ticks are small blood-sucking arthropods present across the UK and mostly found in woods, fields and moorland, as well as parks and gardens. Ticks can't jump or fly - they climb a piece of vegetation and wait for an animal or human to brush past. They are carried on deer, sheep, small mammals and birds and may even be carried into the home on domestic pets. Ticks pass through three life stages: larva, nymph and adult, requiring a blood meal at each stage.

Ticks are known to be particularly prevalent in the Scottish Highlands and across the north and south of England. Ticks are most active from April to October. On average, 5% of ticks across the UK are infected with the Lyme bacteria with regional variation.

The UKHSA monitors the threat of tick-borne diseases and data highlights that tick numbers and distribution have increased, presenting a growing public health threat.

The UKHSA tick surveillance scheme records tick distribution across the UK.

Other tick-borne diseases are much less frequently reported in the UK, but may be acquired overseas; ticks may transmit several co-infections at the same time.

Raising awareness of ticks can reduce the potential impacts of tick-borne diseases.

See pages 17 & 18 for guidance on tick bite prevention and management.

UKHSA Tick Surveillance Map

Other tick-borne diseases

Lyme disease

Lyme disease (LD), or Lyme borreliosis, is a bacterial infection caused by the spirochaete Borrelia burgdorferi, transmitted via the bite of an infected tick.

Its name comes from the town of Old Lyme, Connecticut, USA, where in the 1970s, a cluster of children developed symptoms similar to juvenile arthritis. It was first reported in the UK in the 1980s. Lyme disease is a worldwide problem and the most common tick borne disease in the N. Hemisphere.

There are several genospecies of *Borrelia burgdorferi*, known to cause Lyme disease. Symptoms are often multisystemic.

European genospecies tend to cause more neurological and dermatological symptoms. In the USA, Lyme arthritis is a more common feature and fatal Lyme carditis has been reported. The multisystemic symptoms of disseminated Lyme disease tend to mimic many other diseases.

Incidence

- LD is not notifiable in the UK. UKHSA records only laboratory confirmed cases
- The annual UK incidence is unknown and research is ongoing.
- LD case numbers are highest in Scotland and the south of England.
- Adult population exposure to *Borrelia burgdorferi* is estimated at an average of 0.49 % across England, and 4.2% across Scotland, with regional variations.

An Update on the Estimate of Lyme Disease Incidence in England | CPRD (2024)

Incidence of Lyme disease in the UK: a population-based cohort study | BMJ Open (2019)

CDC ID 9875 credit Jim Gathany

Image credit: CDC

Lyme Resource Centre

Erythema migrans (EM) rash

- An expanding red rash - diagnostic of Lyme disease - a blood test is not required
- Usually develops within 3-30 days of a tick bite. Absent in 30% of cases
- May look like an area of uniform redness rather than a 'bull's eye'
- Usually but not necessarily at the site of the bite. Multiple EM rashes may develop.
- Usually painless. Sometimes itchy. Typically >5cm in diameter.
- Can be difficult to identify in pigmented skin. May become more obvious after a bath or shower.
- May disappear spontaneously without treatment – antibiotics are still required
- Easily misdiagnosed as another insect bite, allergic reaction, cellulitis or ringworm.

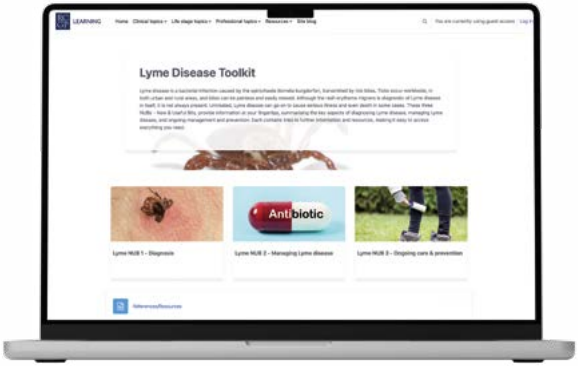
Note

- Patients may not recall a previous tick bite.
- A small (< 2cm) localised area of redness may occur in response to a tick bite but this usually resolves in 3-5 days and is not necessarily an indication of Lyme disease.
- The patient should be advised to take and keep photos of the rash

Examples of different types of rashes can be found in the links shown

CDC - The Many Forms of Lyme disease Rashes

NICE - Lyme disease rash images



RCGP Lyme disease toolkit

The Royal College of General Practitioners (RCGP) online Lyme Disease Toolkit is designed as a quick reference guide for health professionals.

It summarises, the key aspects of LD including detailed information and advice on diagnosis, management, ongoing care and tick bite prevention. Each section contains links to further information and resources.

RCGP Toolkit

Further online resources

RCGP/ LDA eLearning module

This 30-minute online course was developed by RCGP in partnership with Lyme Disease Action and is available to all healthcare professionals in the UK

Centre for Pharmacy Postgraduate Education

(CPPE) has added Lyme disease to the Dermatology e-learning module. This is designed to help pharmacists recognise and manage Lyme disease with confidence.

Diagnosing Lyme disease

Diagnosis can be challenging at all stages of the disease and should be based on a combination of history (including travel), clinical presentation and laboratory testing.

Erythema migrans (EM), if present, is diagnostic of Lyme Disease (LD) but is easily misdiagnosed.

Testing is not required with EM and a negative test does not necessarily exclude LD diagnosis (see pages 11 & 12 for more information on testing).

Early Localised Lyme disease

This may present within days or weeks of a tick bite, with an EM rash and / or flu-like symptoms 'out of season' (e.g. fever, sweats, lymphadenopathy, malaise, fatigue, neck pain, migratory myalgia or arthralgia, brain fog, headaches, paraesthesia).

Disseminated Lyme disease

The tick bite or tick exposure may have gone unnoticed or be long forgotten by the time symptoms appear. Neurological LD is referred to as neuroborreliosis.

Paediatric Lyme disease

Paediatric symptoms can include those seen in adults but may be difficult to assess. Loss of appetite, nausea, behavioural changes are also recognised. Mother-to-baby transmission of Lyme disease is possible in theory.

Facial palsy may occur in early or late Lyme and "In areas endemic with Lyme disease, Lyme disease should be considered as the likely cause of facial nerve palsy in children until proven otherwise."

NICE guideline 95 - Lyme disease

Paediatric facial nerve palsy due to Lyme disease.

Signs & Symptoms of Disseminated Lyme Disease

Early Disseminated Lyme Disease

- Usually occurs within weeks, months after bite

General	Cardiovascular	Neurological
• EM Rash(es) • Flu like symptoms • Fatigue • Myalgia / Arthalgia • Headache • Neck pain/stiffness	• Palpitations • Chest pain • Shortness of breath	• Facial Palsy • Anxiety • Cognitive Dysfunction • Motor/Sensory Neuropathy • Severe neuralgic pain • Meningitis/Encephalitis

Late Disseminated Lyme Disease

- Occurs months or years post bite
- Non-specific or multisystemic symptoms
- Symptoms may fluctuate or migrate over time
- May have periods of recovery with reappearance weeks, months, years later

General	Cardiovascular	Neurological
• Fatigue • GI symptoms • Sleep disorders (disrupted circadian rhythm) • Ophthalmic (uveitis, scleritis, visual changes)	• Arrhythmias (risk of cardiac arrest) • Pericarditis • Myocarditis • Vasculitis	• Facial palsy • Motor & sensory neuropathies • Neuropathic pain • Cognitive Disorders • Dizziness (gait/balance) • Hyperacusis / visual disorders • PoTS (Dysautonomia) • Seizures

Dermatological	Muscoloskeletal	Psychiatrict/Psychological
• Erythema migrans (single or multiple) • Acrodermatitis chronica atrophicans (ACA) • Borrelia lymphocytoma	• Arthalgia / Arthiritis • Myalgia / Myositis • Tendonitis • Bursitis	• Anxiety • Depression • Psychosis • Suicidal ideation

Treatment Guidelines

Prompt antibiotic treatment reduces the risk of further symptoms developing and increases the chance of complete recovery. People diagnosed with Lyme disease (LD), or with a high suspicion of Lyme disease, should be prescribed antibiotics as per NICE guideline 95 – Lyme disease

NICE guideline 95 - Lyme disease

BMJ's Visual Summary - Lyme disease Antibiotic choices, provides a useful summary of NICE guideline 95 – Lyme disease.

BMJ Visual Summary

NICE's Clinical Knowledge Summary (CKS) covers the management of people with Lyme disease in primary care.

Clinical Knowledge Summary

See NICE guideline 95 – Lyme disease

NICE guideline 95 – Lyme disease advises the following antibiotics for the treatment in primary care of people with LD without focal symptoms, but with erythema migrans (EM) rash and / or non-focal symptoms.

Adults & Children aged 9 years and above:

- **Doxycycline**
- **Amoxicillin (if doxycycline is not suitable)**
- **Azithromycin (if amoxicillin and doxycycline are not suitable)**

Children aged under 9 years:

- **Amoxicillin**
- **Azithromycin (if amoxicillin not suitable)**

Note that doses are higher and for longer duration than usually used for other conditions. A second antibiotic course may be required if symptoms persist. Different regimes may be indicated in secondary care for patients with focal symptoms due to LD.

"Misdiagnosis and ineffective treatment have had a pervasive impact on every aspect of my life."

NICE guideline 95 - Lyme disease

Diagnosis - Key Points

- Diagnose and treat LD without testing in people with erythema migrans (EM) rash
- Use combined clinical presentation & testing to guide diagnosis without EM
- Do not rule out LD if tests negative but high clinical suspicion of LD
- Diagnose LD in people with symptoms of Lyme disease and a positive immunoblot
- If LD suspected with a negative test within 4 weeks of symptoms onset - repeat after 4-6 weeks
- If LD suspected with symptoms for >12 weeks but negative ELISA perform an immunoblot

Treatment - Key Points

- Prompt antibiotic treatment reduces the risk of further symptoms developing and increases the chance of complete recovery.
- Dosages are higher and of longer duration than other conditions.
- If clinical suspicion of LD without EM, consider starting treatment while waiting for results.
- If symptoms persist after first course - give 3 weeks of a different antibiotic.
- Warn about possibility of Jarisch-Herxheimer reaction.
- Ongoing symptoms: consider treatment failure, reinfection, organ damage, review diagnosis, secondary care referral.

Acknowledged Limitations

- Lack of robust epidemiological data on LD in UK population
- Poor quality evidence available on diagnosis and treatment
- Evidence on effectiveness of antimicrobial regimens is poor quality, outdated, from small studies
- Testing has limitations (false negatives) - clinical judgement required

NICE guideline 95 - Lyme disease

Testing

Serological testing for Lyme disease (LD) in the UK is 2-tier, consisting of an ELISA followed by an immunoblot if the ELISA is positive or equivocal.

Based on evidence on test accuracy, the NICE guideline 95 committee agreed that

- test results need careful interpretation alongside clinical assessment to guide diagnosis.
- because of the limitations of tests, LD should not be ruled out by negative tests if it is strongly suggested by the clinical assessment.

The test is dependent on an immune response which may be delayed or impaired. Sensitivity is particularly low in early disease, leading to a high number of false negatives.

A negative test result does not exclude the diagnosis. Early treatment with antibiotics or immunosuppressants may abrogate the immune response and can also explain a negative test result. Specificity is high during all stages of disease (false positives rare).

NICE guideline 95 also states

- Laboratory testing is not required for people with erythema migrans
- Consider starting treatment with antibiotics while waiting for the results if there is a high clinical suspicion
- There is no test of disease activity or cure

Routine bloods may be normal, even in unwell patients and other investigations (based on clinical picture) may help to confirm but not exclude LD diagnosis.

Requesting Lyme disease serology

Serum samples for borrelia should be sent to the local laboratory, along with a local laboratory request form and ideally a completed UKHSA or NHS Highland request form. Interpretation of the test can be improved by the level of clinical detail provided e.g. symptoms and onset date, tick bite or exposure history, any travel and treatment history.

- The ELISA test is usually carried out at a local laboratory and reported within 24-48 hrs
- If ELISA is positive or equivocal, then the sample is forwarded to RIPL for immunoblot testing (10-14 days)

UKHSA-Lyme-request-form-RIPL

Lyme disease: sample testing advice - GOV.UK

Lyme disease request form - NHS Highland

Lyme disease and tick-borne infections NHS Highland

Diagnostic Challenges

The multisystemic symptoms of disseminated Lyme disease (LD) tend to mimic many other diseases, resulting in it being described as the New Great Imitator - a comparison with syphilis, the original Great Imitator, caused by the spirochete Treponema pallidum. Conditions which may be mimicked by Lyme disease are shown in the table.

General	Cardiovascular	Neurological
• Long COVID • Myalgic Encephalomyelitis • Chronic Fatigue Syndrome • Irritable Bowel Syndrome • B12 Deficiency • Systemic Lupus Erythematosus • Menopause / hormone related • Medically Unexplained Symptoms	• Arrhythmias • Pericarditis • Myocarditis	• Bell's palsy • Multiple Sclerosis (MS) • Motor Neurone Disease (MND} • Parkinson's Disease • Guillain-Barré Syndrome • Chronic pain • Functional Neurological Disorder (FND)
Dermatological	**Muscoloskeletal**	**Psychiatrict/Psychological**
• Insect bites • Unexplained rashes	• Arthritis • Fibromyalgia • Ehlers Danlos Syndrome • Polymyalgia Rheumatica • Rheumatoid Arthritis (RA)	• Anxiety • Depression • Psychosis • PANS / PANDAS

In 2024, Lyme Resource Centre carried out a Lyme Disease Experience Survey, [N=475] to capture the real-life experience of people with Lyme disease. The survey highlighted over ninety other medical conditions that were diagnosed or suggested to respondents in relation to Lyme disease symptoms, with the most common conditions shown below.

"I was fiercely independent and strong before, now I'm vulnerable and rely on others good will and love. I lost career, family, friends, income, independence. It's hard to do anything now.....I wouldn't wish this on anyone."

Persistent symptoms

Most patients with early Lyme disease (LD) recover with appropriate antibiotic treatment. However, approximately 10–20% of patients, particularly those whose diagnosis and treatment are delayed, experience persistent or recurrent symptoms.

Post-Treatment Lyme Disease (PTLD) is described by Johns Hopkins Medicine Lyme Disease Centre as *a research-defined subset of patients who remain significantly unwell for six months or more following standard treatment for LD*. It is characterized by a range of debilitating symptoms, including severe fatigue, musculoskeletal pain, cognitive difficulties, sleep disturbances, and depression. These symptoms can be prolonged and have a profound impact on patients' health and quality of life.

Research is ongoing into the possible underlying causes of PTLD, which may include persistent infection, chronic inflammation, immune dysregulation, and autonomic dysfunction.

Lyme Disease Treatment & Prognosis

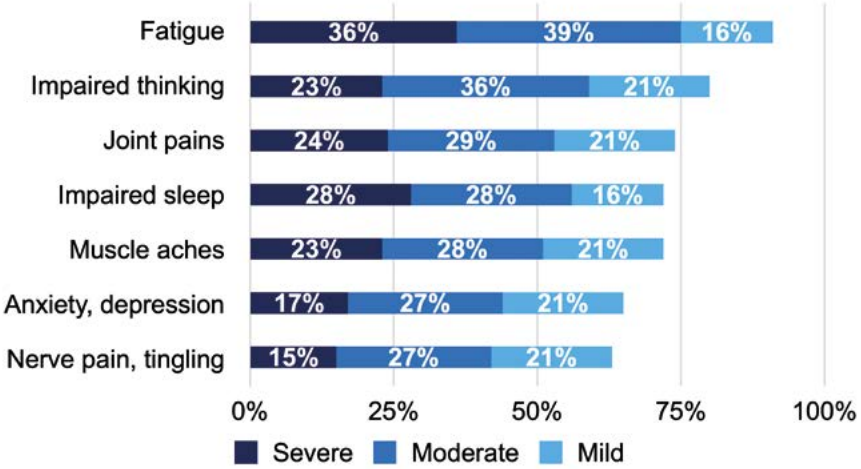
Persistent symptoms

Current treatment guidelines for persistent Lyme disease (LD) are based on four trials, which advised against additional antibiotic therapy. A subsequent biostatistical review concluded that retreatment may, in fact, offer clinical benefits in some cases. (see evidence and reference sources, back cover).

NICE guideline 95 acknowledges that

"The evidence on the effectiveness of antimicrobial treatment regimens used in different presentations of Lyme disease is of poor quality, outdated and often based on small studies".

The Lyme Resource Centre's 2024 Lyme Disease Experience Survey, captured the most common ongoing symptoms



Lyme Disease Experience Survey

Tick bite prevention

Tick bites are easily missed as bites are painless and ticks can be tiny; they may remain attached, undetected for several days. There is no proven minimum time for transmission of infection, though the longer the attachment the greater the risk.

- Avoid exposing bare skin
- Wear long trousers and tuck them into socks
- Wear light coloured clothing so that ticks are more easily noticed
- Insect repellents containing DEET and picaridin are effective against ticks.
- Stick to well-maintained paths and avoid walking in, touching long grass
- Carry a tick removal tool or fine-toothed tweezers
- Carry out tick checks during and after time outdoors - including on children and domestic animals
- Shower and do a thorough tick check after being outside
- Be aware that pets may carry ticks into the home

Access printed tick awareness materials

Tick bite management

- Prompt correct tick removal is key
- Ideally use a tick removal tool or fine tipped tweezers.
- Do not use oil or nail varnish
- Avoid squashing or traumatising the tick as this increases the risk of transmission of infection.
- Clean and disinfect the site of the bite
- Check for multiple tick bites - nymph ticks may be as small as a poppy seed.
- Children are more likely to be bitten above the waist, especially around the hairline.

Tick removal tools

Use a tick removal device to remove ticks correctly – see the links below.

- **Tick twister**
- **Card remover**
- **Fine-pointed tweezers**

Following a tick bite or tick exposure, watch for skin rashes, flu-like symptoms or other unusual symptoms for at least 30 days and seek medical help if symptoms develop.

Image Credit: Lauren Bishop CDC ID 28384

Image Credit: Ticktwister

How to use a tick twister

How to use a card remover

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To find out more about Lyme Resource Centre (LRC) and access more information and resources, visit our website

www.lymeresourcecentre.com

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All quotations from Lyme Resource Centre's Lyme Disease Experience Survey | Published October 2025

Lyme Disease - What Health Professionals Need to Know (online version) and Resources, Evidence & Research Sources

An online version of this booklet and information on further resources, evidence and research sources used can be found on our website via the QR code below

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