

Lyme Disease Briefing

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In summary...

We need **greater awareness of Lyme disease** (by public and health professionals), **better monitoring of cases, a better test, treatment options for late diagnosed patients, research into why some people stay unwell** after acute stage treatment, and **more training for health professionals**.

Until then, **cases will continue to rise**, there will be more **missed opportunities to treat the disease effectively** at the acute stage of the disease and more Lyme disease patients will go on to suffer from **difficult to treat, long term symptoms**, turning their lives and the lives of their loved ones’ upside down.

Lyme disease explained

Lyme disease (borreliosis) is a **tick-borne bacterial infection** caused by the spirochetes from the Borrelia family. Transmission of Lyme disease can occur when bitten by an infected tick. It's the most common tick-borne infectious disease in the northern hemisphere and there are multiple strains of the bacteria.

Lyme disease is endemic in many parts of the United Kingdom, particularly in **woodland or heathland areas** but disease-carrying ticks **can also be found in city parks and urban gardens**.

Lyme disease can be a **complex condition** and many aspects of the illness are contested and debated.

If caught early, Lyme disease can be easy to treat. However, complications can occur if the infection is left untreated. '**Chronic Lyme disease**' is not a medically accepted term in the UK. Independent Lyme treating practitioners use it to describe long-term symptoms and complications associated with the disease and also to describe what happens if the patient is not diagnosed early on after being infected or if initial treatment has failed. We use the term '**late**' or '**late stage**' Lyme to differentiate between patients with recent and long term infections.

Symptoms

Symptoms can start with an **erythema migrans** (EM) rash, often described as a **bull's-eye rash**, but the rash can also be more **irregular**, which sometimes leads to a misdiagnosis of ringworm or cellulitis. It's important to note that not every Lyme disease patient will experience or remember a rash, as figures state that **the rash appears in two out of every three Lyme disease patients**. The rash may not appear straight away. We advise people to draw a ring around suspicious looking rashes to track any potential changes.

Symptoms of Lyme disease can include **malaise, unexplained flu-like symptoms, soreness and achiness, light and noise sensitivity, cognitive problems, fatigue, a stiff neck, facial palsy, numbness and tingling**. Left untreated, the infection can spread anywhere in the body, leading to around **70 recognised symptoms**. People can develop issues with their endocrine and neurological systems and experience musculoskeletal, **cardiac**, dermatological and neuropsychiatric problems.

Lyme disease in the UK

Laboratory-confirmed cases of Lyme disease in England and Wales have risen steadily since reporting began in 1986, although yearly fluctuations have been observed. Mean annual incidence rates for laboratory-confirmed cases have risen from 0.38 per 100,000

population for the period 1997 to 2000, to **a peak of 2.77 cases per 100,000 population in 2018**. Official figures are not complete due cases not being recorded properly during the pandemic.

Co-infections have been found in the UK and yet the ignorance surrounding the possibility of these other tick-borne infections is even worse than that of Lyme disease. More attention and publicity needs to be given to these infections so that they can be treated as well.

Babesia and **Anaplasma** are examples of other infections carried by ticks in the UK, yet there is very little awareness publicly or professionally about them. **Ticks have now been found carrying Tick-Borne Encephalitis in the UK** and now that the first domestic case has been confirmed, this issue is only likely to grow as well. There is actually a vaccine available for TBE. Is it likely to become available in the UK?

The situation in the UK is dire. We see mistakes in diagnosis, testing and treatment. False negative results are a big issue with the current testing available and Lyme disease should be a clinical diagnosis. Patients are being dismissed if they have negative Lyme disease test results, people are becoming housebound, disabled and even suicidal. We also see patients driven to self-treating or paying for expensive private treatment abroad. This represents an unacceptably high cost for individuals, society and the economy.

The problem with Lyme disease

1. **Public awareness is low.** Awareness of how to prevent tick bites and the consequences of contracting Lyme disease are not widely known. People will buy repellent for trips abroad but not necessarily think they need to protect themselves in parks and woodland or their back gardens.
2. **Awareness from health professionals is low (but improving!)** There is variability in knowledge among NHS clinicians. Some have little or no knowledge of Lyme disease and others are updating their knowledge by familiarising themselves with the **NICE Lyme disease guideline** and completing the **RCGP Lyme disease** online course.
3. **Testing is unreliable.** At present, there is no test which can rule out Lyme disease as current testing is flawed. False negative results are possible and there is also no test to show you have been cured. **Antibody tests can be difficult to interpret.**
4. **No recognised treatment protocol for late stage infections (NHS treatment/NICE Guideline - only suitable for acute infection).** Diagnosis is difficult due to absence of a reliable test and a lack of awareness of clinical symptoms. The NICE Guideline for Lyme disease applies to acute/recent infection only. GPs have no guideline or recommended treatment for late stage patients. Symptom relief is offered to late Lyme sufferers such as painkillers and antidepressants but there is no treatment being offered for underlying infection.

5. **Misdiagnosis due to similar symptoms with other conditions.** Due to the variability in symptom presentations from patient to patient, and sometimes due to no recollection of a tick bite, patients can be seen and misdiagnosed by many consultants from various specialisms. The symptom constellation is quite recognisable to doctors who are experienced in diagnosing and treating Lyme disease, however when patients visit various consultants, they do not always put the pieces of the puzzle and the patient's diagnosis together.
6. **Controversy around the late stages of the disease.** Stigma used to be huge for Lyme disease patients. We would regularly hear of patients not being believed or being accused of 'wanting' a Lyme diagnosis. With greater awareness of acute infections, this does seem to be subsiding a little, with patients reporting more empathy and understanding from their loved ones, colleagues and GPs.

There are also a wealth of conspiracy theories, political debate and legal action against Lyme treating practitioners worldwide. The history and politics around Lyme disease are too complex for most people to want to explore in detail and there is often a vague feeling of distrust, murkiness and lack of credibility when it comes to the disease and diagnosis. This only serves to add to the isolation felt by individual patients who have no interest in the controversial history of Lyme and only want to get well and get their lives back on track.

Why does it matter?

Acute cases not being picked up early enough, leading to more complex, late stage cases.

Not only is this devastating for the individual, but it has a much wider impact on society as patients may be unable to work and need to be financially supported by the benefits system. Parents with Lyme disease are sometimes unable to look after their children or themselves due to invasive symptoms, and this puts pressure on patients' wider support system.

Misdiagnosis prevents the patient's opportunity for correct treatment.

It is not uncommon for patients within our Online Community to initially be misdiagnosed with a range of conditions, including depression, **chronic fatigue syndrome/ME**, multiple sclerosis, and even **stroke** and then go on to see improvements in their health after antibiotic treatment for Lyme disease.

Impact on children's health.

Difficulties with diagnosis, coupled with health professionals' lack of awareness of correct dosages required to treat acute Lyme disease, can lead to children being either **under-dosed** with antibiotics or **misdiagnosed**.

This leaves some children with acute Lyme disease at risk of developing a longer term, more serious and complicated infection to treat. Children with untreated or misdiagnosed Lyme disease often cannot attend school or university for months, or years at a time.

Late stage Lyme patients falling through the cracks.

Many patients are left unable to get a correct **diagnosis** or **treatment**, **unable to work and struggling to access benefits**. If they can afford to, some patients **seek treatment from private clinics**, often abroad and out of desperation to get well.



Watch our short animation on Living with late Lyme disease.

What would improve the situation for Lyme patients and prevent further infections?

We believe immediate focus should be on **preparing for the next tick season, improving treatment for existing patients** and **pressing for a generous research budget**.

1. Greater public awareness

Greater public awareness would result in less infections and more understanding for late Lyme patients.

Signage and leaflets

- Signage in green and recreational spaces
- Pharmacies
- GP surgeries
- Young people's groups
- Outdoor sports and leisure pursuits e.g. golf, cycling, rambling, hiking
- Churches and community centres

Sharing digital content via trusted sources - i.e. NHS organisations, local councils.

We are doing what we can with a very limited budget. A larger scale, government funded campaign would be more effective.

LDUK 2023 Awareness Campaign in numbers:

- 20 landmarks lit up green for Lyme awareness.
- Campaign **press release** was picked up by over 35 UK newspapers.

- Exhibited at Primary Care and Public Health Conference with **6,000** health professionals attending.
- Our **awareness animation** was displayed on **650** pharmacy screens.
- We sent out **10,000** leaflets, **10,000** tick cards and **1,250** posters in **awareness packs**.
- Awareness posters displayed in **3,000** GP surgeries across the UK.
- Awareness information emailed to **20,000** school leaders.
- Our **campaign video** had **50,000** views on social media. Scan the QR code below to watch.



UKHSA have shared posts this summer; **Tick-borne disease in the UK: stay safe this spring and summer**. Watch our **‘Enjoy the Outdoors Safely’ animation**.

2. Better monitoring of cases

Currently, only **seropositive cases are logged** by **UKHSA** and shown as the official figures. Acute cases are diagnosed by the presence of **erythema migrans rash** (without need for a blood test). A more accurate number of cases would be known if a logging system was established to include those diagnosed by blood test **AND** those diagnosed by presence of Lyme (EM) rash.

As climate change seems to be giving us warmer/wetter winters with ticks in certain areas staying active during the winter months, would it be sensible to make tick-borne diseases notifiable?

It’s crucial to help understand the prevalence of infections and examine the impact of interventions to reduce them.

3. A better test

If we had a direct test for active infection, it would stop the ability to blame positive tests on being a false positive or a cross-reaction. It would also tell us if the person's treatment has “cured” them.

Essential for correct diagnosis to be made and to assess treatment efficacy.

4. Treatment options for late stage patients

Concerning treatment of patients, the draft NICE guideline made it abundantly clear that there is an alarming dearth of good quality evidence for effective treatment protocols at all stages of the disease. **Until there is better primary evidence, we would like to see clinicians encouraged to exercise professional judgment in diagnosis and treatment decisions.**

We would recommend that UK doctors are encouraged to visit, observe and learn from established **ILADS American and European Lyme specialists**. LDUK would be pleased to use its contacts to facilitate such opportunities. It is critical to explore innovative ways to improve care for current Lyme disease patients as soon as possible.

5. Research into why some people stay unwell after standard treatment

A research budget needs to be established urgently to fund the NICE research recommendations and other gaps identified. Improvements in research, treatment, education and awareness must be mutually supportive and mutually dependent, each increasing the effectiveness of the other. There is otherwise a danger that issues are addressed in an ad-hoc fashion, with no cross-fertilisation or resource-sharing.

UKRI and DEFRA have invested in important research on tick habitats and behaviour, but there is not currently any government funded research into testing or treatment.

6. More training for frontline health professionals

Doctors need to be aware of, and compliant with, current guidance and best practice and especially need to be made aware of testing limitations. The information received by them from the RIPL lab should be explicit on this point. Until we have a better test, it is not possible for a diagnosis of Lyme disease to be made on blood tests alone. Change is needed in the medical system to give greater emphasis to clinical diagnosis, only supported by, and not limited by testing. Establishing better testing is paramount.

Watch our **'Key Points in Testing and Diagnosis'** Animation to update health professionals on the NICE Guideline for Lyme disease.

Front-line staff, including pharmacists, practice nurses and A&E staff need to be able and equipped to remove ticks safely, and can recognise an EM rash and other early symptoms.



Lyme Disease UK is a registered charity with an Online Community of over 13,000 members, the majority being from the UK. As well as supporting our members, Lyme Disease UK campaigns for **better awareness, diagnosis and treatment of Lyme disease**. We are stakeholders in the NICE Lyme disease guideline process and **submitted a response to the draft guidelines in 2017**.