

Lyme Disease in the UK

Briefing for MPs, November 2016



Basic facts.

- Lyme disease or Lyme Borreliosis (LB) is a bacterial infection transmitted to humans by the bite of an infected tick.
- Animal studies have failed to prove transmission by anything other than ticks, though there are possible anecdotal reports of transmission by mites or insects. Placental transmission has been reported in autopsies of stillborn children, but congenital infection as a definite means of transmission remains an uncertainty.
- Ticks are small blood sucking arthropods related to spiders and feed on a variety of hosts: mice, birds, small mammals and larger mammals such as badgers and deer. From some of these hosts ticks may pick up pathogens; the Lyme disease bacterium is the most common, but there are others with an unknown prevalence.
- Ticks carrying LB occur throughout the UK, including in town parks and gardens.
- Ticks can be very tiny - the stage that most often transmits LB is the size of a poppy seed, though it grows larger as it becomes engorged with blood.
- UK studies report about 1 in 3 people with Lyme disease did not see a tick.
- LB can be mild and can resolve spontaneously but disseminated LB can affect almost any part of the body, and have a catastrophic impact on a patient's life.
- The diagnosis of Lyme disease can be challenging because symptoms may overlap with a wide range of other conditions.

What has made LB contentious?

- If a tick bite is not seen and the typical rash not noticed a patient presents with non-specific symptoms of unknown origin.
- The first report of Lyme disease in the UK was in 1977 and many doctors have never seen a case. Experience of complex cases and even typical cases is limited.
- Because of the lack of UK expertise, reliance has been almost exclusively on the blood test which detects antibodies to the disease. The specific antibodies tested for do not always develop in some people for a range of reasons, so negative test results in cases of LB can occur. (1)
- Antibodies (and therefore positive test results) can persist for months, sometimes years, and there is no test yet of either cure or persisting disease.
- The previous head of the Health Protection Agency (HPA) Lyme disease reference laboratory (retired 2012) promulgated a very certain view to colleagues, officials and the general public via the HPA website and other communications maintaining
 - LB blood tests had a >99% chance of being positive in disease of more than 6 weeks duration;
 - standard antibiotic treatment was usually successful, remaining symptoms were likely to be from another cause and chronic LB should not exist;
 - patients were "anti-science".

This probably created a prejudiced view of LB amongst UK health professionals leading to a dogmatic approach to diagnosis and treatment which still exists. (2)

- A recent large-scale European meta-analysis of the diagnostic accuracy of Lyme serology tests has highlighted the limitations of currently available serology test kits and shown that previous studies have often been prone to bias. (3).

- Although early treatment is almost always successful, the best treatment in late-diagnosed cases is unknown and some people fail to recover completely following the currently recommended course of antibiotics.
- It has been proved that the bacteria can survive recommended courses of antibiotics and persisting symptoms could in any one case be due to persisting disease, and autoimmune reaction of tissue damage. There is currently no test to confirm this. Repeat courses of antibiotics have been used successfully in the UK.
- Because many UK doctors (perhaps most) have absolute belief in blood tests and a belief that a standard course of antibiotics cures the infection, some patients go abroad in search of tests which they hope will confirm Lyme disease. Some go in search of additional treatment options including long term or combination antibiotic treatment and a range of alternative therapies where data from clinical outcomes may be unavailable. The personal and financial cost incurred by testing and treatment abroad is substantial and the opportunity for the NHS to remain involved, document any response to treatment and monitor outcomes is lost.
- There are private overseas laboratories which will carry out and interpret certain tests which are not specific for Lyme disease and not licensed for diagnostic use.
- The continuing core uncertainties in diagnosis and treatment create inevitable tension between patients and NHS healthcare providers.
- There is not only damage to the reputation of the NHS but a huge financial cost because of this situation:
 - patients with chronic symptoms experience multiple referrals to different specialties and repeated GP visits in attempts to find an answer to ill health;
 - patients are often out of work or cannot function in their jobs and children may miss vital schooling;
 - questions and complaints are submitted to various authorities.
- It is probable that if the current situation continues, doctors will be referred to the GMC and there may be expensive NHS litigation if cases are misdiagnosed or managed inappropriately.

What has been achieved in the last 3 years?

- Dialogue with the Department of Health which now has a better understanding of the problems, although they have reduced resources.
- A House of Lords debate in October 2015 at which the Minister, Lord Prior of Brampton, in his response said
 - "We can and must do more to raise awareness."
 - "Patients need to have access to physicians with an interest in Lyme disease. Since the disease can be present in many different ways and can be confused with other more life-threatening conditions, in future this could be best done by establishing a network of interested NHS practitioners across the country with multidisciplinary experience."
- Dialogue and some common understanding with some staff at the Public Health England (PHE) Lyme disease reference laboratory at Porton with whom LDA are able to discuss challenging cases and possibly shed light on negative and equivocal test results.
- An on-line training course for GPs created in a partnership between the Royal College of General Practitioners and LDA, and funded by LDA.
- The start of a process to draw up a NICE guideline for diagnosis and treatment, expected to be published in July 2018.
- The start of some research projects to investigate the incidence of LB in the UK and explore improved testing. These are unlikely to report for at least 2 years.

What needs to be done?

There is no doubt that we need better tests, however, these are already the focus of research projects in both Europe and the USA. We also need trials of other treatment options, but these are likely to take years before any useful results are available.

So concentrating on what may realistically help us now:

1. Crucially: develop some clinical expertise in the UK

The current level of knowledge in the NHS is very low. Doctors appear not to understand the tests, the epidemiology or the disease itself. This is what drives most of the patient frustration and has an impact on patient welfare and safety.

A previous national clinic folded after a brief trial primarily because of poor planning and overwhelming numbers. Since then LDA has worked well through GPs facilitating referrals to one NHS Trust and this has led to a positive outcome for a small number of complex cases. The consultant leading this clinic has now retired and progress has stalled. LDA now has nowhere similar to suggest for patients and no source of expertise to recommend to doctors. *"Please let me know of a Lyme disease specialist?"* is the most common request from patients and doctors.

We suggest **the commissioning of a pilot national clinic**, working along the lines that LDA has developed with an effective triage system to concentrate on those patients with a reasonable pre-test probability of Lyme disease. A dedicated LB clinic would provide healthcare staff with direct experience, enable the development of an advisory resource to the rest of the NHS, provide data to demonstrate outcomes from repeat treatment and act as a developing blueprint for regional clinics.

There is very little research evidence to inform treatment decisions so this has to be learnt from experience and from dialogue with doctors in Europe and the USA who have seen and treated more cases. PHE have started this dialogue, but as far as we know few infectious diseases consultants have attended any international conference on the subject, or spoken with overseas doctors.

Tick-borne diseases are on the rise in the UK causing considerable morbidity, and commissioning a clinic needs to begin now.

2. Review the known information on other tick-borne diseases.

Other tick-borne infections are known to be present in the UK. They complicate diagnosis and treatment, but doctors are generally unaware of them and they are rarely tested for.

There are several universities working in this area but no-one has reviewed the literature and established the gaps in our knowledge. There is no advice for doctors on these diseases. They remain an unacknowledged risk of unknown proportions, and in our view Public Health England should commission a review.

3. Make more effort to raise awareness.

There is evidence from Europe that a consistent and robust public health response to Lyme and tick-borne diseases may be effective in preventing and reducing the burden of Lyme disease. (4)

"An ounce of prevention is worth a pound of cure." - Benjamin Franklin.

Summary

There is no doubt that public welfare and safety is at risk from the current lack of medical knowledge and interest and that Lyme disease is a drain on national resources.

There are ways to improve services, knowledge and awareness within current ways of working. Considerable advances can probably be made without incurring significant costs.

Further reading:

- 1) An explanation of negative Lyme disease tests. LDA Newsletter January 2015 see page 3. <http://www.lymediseaseaction.org.uk/wp-content/uploads/2015/01/LDA-Newsletter-Jan-2015.pdf>
- 2) A video (17m 30 s) giving a historical perspective. From LDA's 2013 conference <https://www.youtube.com/watch?v=uXyHYQVoa84&feature=youtu.be>
- 3) Leeflang M.M.G. et al. The diagnostic accuracy of serological tests for Lyme Borreliosis in Europe : a systematic review and meta-analysis . BMC Infect Dis. BMC Infectious Diseases; 2016;16.
- 4) Hofhuis A. et al. Decrease in tick bite consultations and stabilization of early Lyme borreliosis in the Netherlands in 2014 after 15 years of continuous increase. BMC Public Health. BMC Public Health; 2016;16(1):425.

For any specific queries, printed copies of leaflets or for a telephone conversation with either Stella Huyshe-Shires (Chairman) or Dr Sandra Pearson (Medical Director), please email lobby@lymediseaseaction.org.uk.

Lyme Disease Action

Lyme Disease Action (LDA) is a [UK registered charity](#) formed in 2003. Accredited to NHS England's Information Standard, the charity's main activities are:

- producing quality information on ticks and Lyme disease;
- attending medical conferences and exhibitions to increase knowledge amongst health professionals;
- running an annual conference;
- responding to national and international requests for information on Lyme disease from patients and health professionals;
- developing working relationships wherever possible with the Department of Health, Public Health England, research institutes and universities.

LDA's income is from public donations and the charity has no premises or employees.