



## Suggested referral pathway for patients with symptoms related to Lyme disease

### **Patients presenting to a GP for the first time**

1. Patients seen by a general practitioner with an erythema migrans rash at the time of consultation should be treated with antibiotics as Lyme disease.
2. Patients without a rash but with symptoms suggestive of Lyme disease and a credible risk of tick exposure should have serum taken and sent to an NHS laboratory for testing. Note that Lyme disease is endemic throughout the UK. The decision to treat on clinical suspicion should be based on exposure history and the presenting symptoms. Note that up to a third of cases of Lyme disease do NOT have a classical rash, if any at all, and absence of rash or any recollection of a tick bite does not exclude the diagnosis. The most common early symptoms in adults are flu-like symptoms of aching, fever, headache, fatigue, sweating, joint pain, light and sound sensitivity, abnormal skin sensations (tingling, numbness, itching), stiff neck. Facial palsy, headache and fever in tick season (April to October) has been shown to predict Lyme disease in children.

Lyme carditis presenting as heart block is an uncommon early sign requiring urgent cardiology referral.

In a significant proportion of children neurological examination may be normal. The antibody response in the Cerebrospinal fluid may precede that in serum, so it is important to consider referral for lumbar puncture and further testing.

3. Patients with tests that are positive from an NHS laboratory should be treated if presenting symptoms and signs are compatible with active Lyme disease.
4. If an initial serological test is negative, but symptoms persist it is worth sending a repeat sample 3-4 weeks after the initial test as the antibody response to Lyme can take time to develop and fluctuates in early disease. Patients with positive results who have not already been treated should be treated with antibiotics.

5. Note that:
  - early treatment is important to prevent spread of the disease to other tissues and avoid late complications
  - be aware that early treatment with inadequate antibiotics or immunosuppressants abrogates the immune response and can explain a negative test result

GPs and specialist medical practitioners can obtain advice from Rare and Imported Pathogens Laboratory (RIPL) staff in working hours on 01980 612348.

### **Patients with persisting symptoms after treatment for Lyme disease**

1. Symptoms may persist for several weeks after treatment for Lyme disease and if gradually improving do not need treatment.
2. If symptoms persist or get worse then the Lyme disease serology should be repeated on fresh samples. Relapse has been documented. The GP should also consider and investigate other causes if appropriate at this stage. Patients can be referred to the relevant specialist clinic if necessary. Patients with significant neurological symptoms should be referred to a neurologist or infectious disease physician for investigation. If Lyme disease is still the most likely diagnosis the *medical practitioner* can discuss the case with the RIPL at PHE Porton Down on 01980 612348 in normal working hours for advice on further investigation and testing.

### **Patients with positive tests from non-NHS laboratories**

1. Patients with positive tests from non-NHS laboratories should have repeat serology performed through an NHS laboratory. If these are positive, management should follow the pathway above. Some private laboratories use accredited tests, so advice should be sought from RIPL.
2. Patients whose private results are not confirmed should be investigated according to their symptoms and clinical findings, with referral to appropriate specialist based on the findings.
3. NHS laboratories can offer a wide range of tests for potential causes of these symptoms. In addition, a number of additional bacterial and viral agents that are associated with tick bites can be tested for by RIPL. GPs and specialist medical practitioners can obtain advice from RIPL staff.

## Advice for patients

1. In the first instance patients should discuss their case with their GP, who is best placed to help them, having access to their full medical history and any investigations (blood tests, scans etc) that have been carried out.
2. Lyme Disease Action offers a help service for patients and has a website addressing many frequently asked questions on Lyme disease ([www.lymediseaseaction.org.uk/](http://www.lymediseaseaction.org.uk/)). Information is also available through the NHS Choices ([www.nhs.uk](http://www.nhs.uk)) and PHE ([www.gov.uk/phe](http://www.gov.uk/phe)) websites.

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