

NHS treatment for acute Lyme disease

The NHS will not normally provide **prophylactic (preventative) treatment** following a single tick bite if there is no reason to suspect Lyme disease although the RCGP Lyme Disease toolkit does say this can be considered for certain high risk cases. However, you may wish to go to your GP to seek their advice and get the bite listed on your medical records.

Additionally, if you have **multiple bites** at the same time then you may want to discuss the possibility of preventative treatment with your GP.

Early cases of Lyme disease are normally treated with antibiotics. Please note that the type of antibiotic varies depending on whether you are an adult, a child, or pregnant. It is also important to ensure that you are receiving the maximum amount of treatment recommended by the NICE guideline (**each course should be between 17-28 days depending on the age of the patient, the type of antibiotic prescribed, and symptoms**). Doctors who are not familiar with the guidelines might not be aware of the high dosages needed to treat Lyme disease so it is worth discussing this with your GP. **It is essential that you complete each course of antibiotics.** Make sure you have an appointment with your doctor before the end of the course to review your progress **if symptoms persist**. You can see an infographic of treatment protocols [here](#).

The NICE Lyme disease guideline states; 'consider a second course of antibiotics for people with ongoing symptoms if treatment may have failed'. The second course of antibiotics is likely to be a different type to the first. **Be aware of the possible Herxheimer reaction which is a worsening that can occur as the bacteria is killed.** It is important for your doctor to distinguish between this reaction and a drug allergy.

It is crucial to note that **you can be reinfected with Lyme disease**. Having had the condition already does not make you immune.

A blood test is not available that can say if antibiotics have eradicated the infection so testing after treatment isn't necessary.

Note: Be aware that **doxycycline can make you incredibly sensitive to the sun** even in winter. Ensure you **stay upright for 60 mins after taking it**, and always take it on a full stomach. Some people like to take a course of **probiotics, either with or after a course of antibiotics** e.g. a good quality, multi strain probiotic with a high CFU (the number of bacteria). If unsure, discuss with your doctor. You can find more information on taking doxycycline [here](#).

The NICE guideline says 'do not routinely offer further antibiotics' following two courses. This **does not mean it is not possible to make a case for ongoing treatment** if improvement is experienced on treatment followed by a decline when treatment is withdrawn.

The NICE guideline frequently advises referrals to a 'specialist'. It is important to be aware that currently, there are **no Lyme disease specialists on the NHS**. The specialist's role is likely to be ruling out other causes and providing support with symptoms rather than treatment of the disease.

What You Can Expect from an NHS Doctor for Acute Lyme Disease

- ✓ **A diagnosis of Lyme disease and immediate treatment if you have an EM rash** without the need for a blood test.
- ✓ **Testing** (at the right time and repeated as per the guideline) if Lyme disease is suspected.
- ✓ **Immediate treatment if there is a high probability of Lyme disease** without an EM rash and without waiting for test results.

If the Lyme disease test continues to be negative, **to be clinically assessed** for Lyme disease instead as well as for other conditions, including co-infections. The NHS cannot test for all co-

- ✓ infections and these tests can also miss infections but your GP can request a 'Full Co-Infection Panel' from RIPL, the lab who completes the second part of the Lyme disease test. It can be possible to be positive for another tick borne infection even if the Lyme disease test is not positive.
- ✓ If a Lyme disease diagnosis is made, the **full amount of appropriate treatment** recommended by the NICE guideline (a course of antibiotics ranging from 17-28 days, with a second course if symptoms continue). The NICE guideline contains separate treatment tables for adults and children.
- ✓ See antibiotic treatment tables in the NICE guideline **here**.
- ✓ Also see British Medical Journal's antibiotics infographic **here**.
- ✓ Consideration of **further treatment or a referral to a specialist if any symptoms continue** (note that no Lyme specialists currently exist in the NHS). If you are referred to a specialist, it will depend on symptoms present as to which specialists you will be referred to. e.g. infectious diseases, neurology or rheumatology.

If your doctor is not treating you in accordance with the NICE Lyme disease guideline, you may wish to ask them to put down in writing the reasons why.

Further Information

Please see www.lymediseaseuk.com for more information.

We offer a support email helpline for information and support but please note that this does not constitute medical advice: support@lymediseaseuk.com

A list of frequently asked questions can be found [here](#).

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