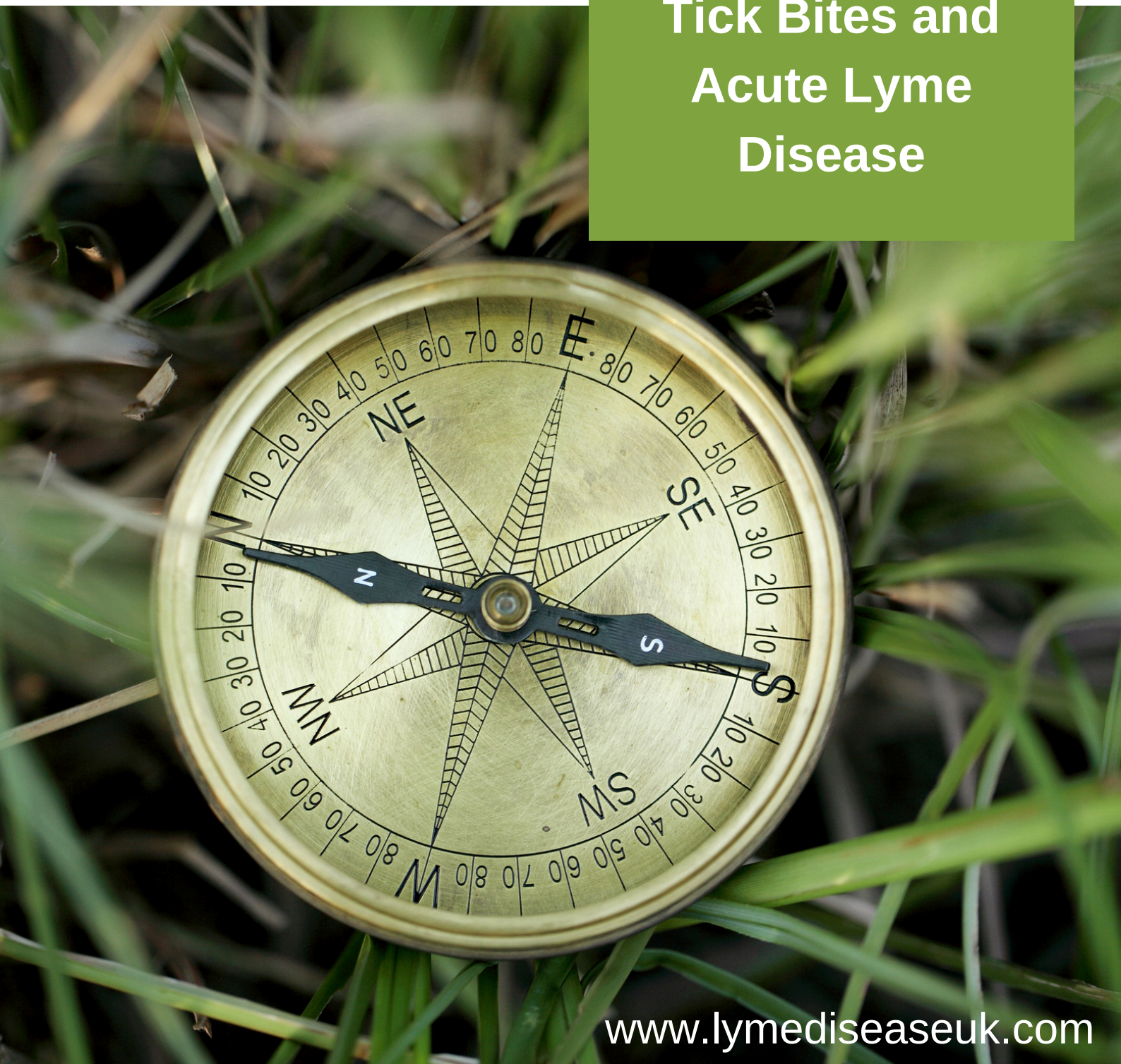
LDUK
LYME DISEASE UK

# Lyme Disease

## Information for Patients on Tick Bites and Acute Lyme Disease



www.lymediseaseuk.com

# Contents

## Getting Started

Please scroll down to the relevant section in the guide relating to your situation. This guide is written for UK residents based on the situation in the UK.

There is now a NICE guideline for Lyme disease, which can be found here. It may be useful to **print and take to your GP.**

There is an online RCGP course for medical professionals and patients which you can access here.

There is also the Spotlight project in partnership with Lyme Disease Action, as well as our awareness animation which covers the key points on diagnosis, testing and treatment which can be found here.

LDUK's comments on the **NICE guideline and its limitations** can be found here. It is lacking in terms of guidance on how to address late stage Lyme disease, however it will hopefully enable new cases to be treated promptly.

## Tick Removal

If you find an attached tick, it is very important not to distress it in any way by using any kind of oil, a match, your fingers, blunt tweezers or anything else not designed for the job.

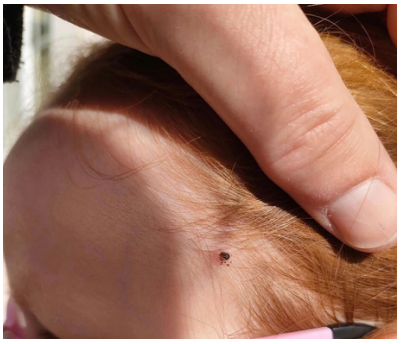
If you have not yet removed the tick, **take a photo** of it whilst embedded (but do not delay removal if you don't have a camera to hand) and then **quickly, and safely, remove the tick** using the guidance available here.

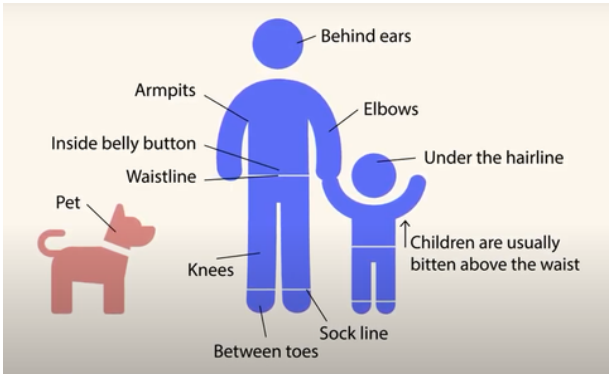
If you do not have a tick removal tool, it is possible to use dental floss, a fine thread or a hair and tie a loop around the mouthparts of the tick and pull smoothly upwards and outwards. Do not twist.

**If your attempt to remove the tick fails, please seek medical advice immediately from a GP or NHS walk-in centre. If you cannot access these services, call NHS 111 for advice. If you notice the tick's mouthparts are still embedded, there is no need to seek advice, as the body will expel them like any other foreign body, but it's a good idea to keep an eye out for any localized infection around the area that might require antibiotics.**

## Checking for Further Tick Bites

**Complete a thorough tick check** to ensure you don't have any other bites elsewhere, remembering that ticks can be as small as a poppy seed and bites can be easy to miss. Ticks also like to hide, so carefully check areas such as between toes, in the groin, under your waistband and particularly for children, around the hairline.






If you know when you were bitten and you were with other people, advise them to check for ticks or perform a check on them. Also thoroughly **check your pets**, remembering to look in paws, mouths, ears and under legs.

## Do I Have Lyme Disease if I've Been Bitten by a Tick?

Although you have been bitten, it does not mean you have definitely contracted Lyme disease, as not all ticks are infected. Ticks are endemic throughout the UK and infected ticks have been found in every region. You can also be infected with Lyme disease in other countries.

People are often told that a tick needs to be attached for a certain amount of time in order to transmit Lyme disease. However, **a minimum attachment time for transmission has never been established.**

That said, it is critical that Lyme disease is diagnosed and treated promptly in order to avoid long-term health problems.

## I Don't Remember a Bite. Could I have Lyme Disease?

It is possible, as **tick bites tend to be painless, can be very small and are easily missed**. This is recognised by the NICE guideline. This is why it is important to be aware of the early symptoms of Lyme disease.

## Monitoring the Bite Site and Symptoms

**Draw around the bite site** with a pen and **take another photo**. Or, place a coin next to the bite site and take a photo so that any changes in size can be tracked. Keep a photo record of any changes and look out for any rashes which may appear.

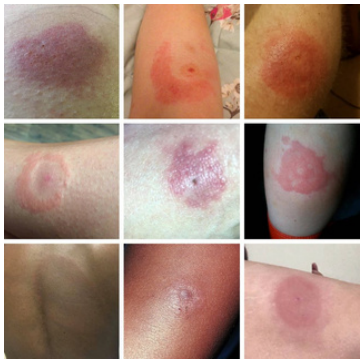
It is worth noting that some people will notice some irritation, swelling and redness during the first couple of days following a bite which then recedes. This can be a histamine reaction to the bite and does not always mean that Lyme disease has been contracted.

Start keeping a close eye out for any symptoms during the coming days/weeks/months, remembering that symptoms may have a delayed onset and fluctuate. Some early symptoms are listed **here**. Also be on the lookout for changes in mood/behaviour, particularly in children, as these can be the first noticeable symptoms and they may be too young to articulate problems. You may find our guide to supporting a child with acute Lyme disease helpful which you can access **here**.

**If you do develop any symptoms, be sure to keep a detailed symptom diary and seek medical attention quickly.**

## For People with A Rash

If you have a rash that appears immediately after a bite it is more likely to be a **local histamine reaction** to the bite. However, there is a specific rash known as an **EM (Erythema Migrans)** rash that indicates Lyme disease. In its most classic form, it can resemble a bull's-eye, but the key characteristic is the spreading of the rash. It is important to be aware that **EM rashes can be varied in appearance** but can appear as a solid rash or have a bruise-like appearance. They can look very different on darker skins and may be difficult to spot. Examples can be found here.

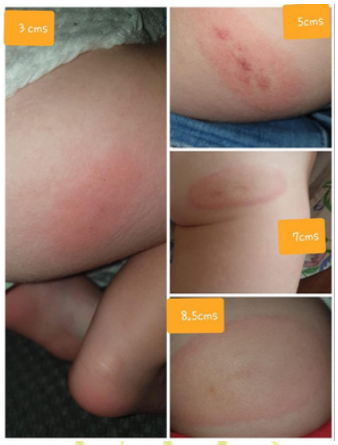


Many people don't get an EM rash but if you do, it means you have been infected with Lyme disease. A blood test is not necessary for diagnosis and treatment for Lyme disease needs to start immediately. The rash is usually delayed after a bite and can appear any time between 3 days to 3 months after a bite. An exception to this could be if attachment time is very long, then infection may have happened earlier than indicated by tick removal time or if someone had received more than one bite in the days before that they had not noticed. Rashes tend to be painless, flat and not itchy. Draw around the rash with a pen and take a photo or place a coin next to the bite site and take a photo so that changes in size can be monitored. Seek medical attention quickly.

If you don't know what you were bitten by and you/your doctor isn't sure whether your bite is an EM rash or an allergic reaction, you could ask your doctor or pharmacist for advice on taking an antihistamine and/or using an **antihistamine** cream. If you are experiencing an **allergic reaction**, you would expect the rash to calm down quickly. Similarly, if your doctor isn't sure if it is Lyme disease or a fungal infection you would expect fungal treatment to improve the rash.

If the doctor isn't sure whether it is Lyme disease or **cellulitis**, both are serious conditions and require immediate treatment. Some rashes can be very hard to discriminate from other conditions like cellulitis and in this situation, the GP should take care to prescribe an antibiotic that will cover both eventualities until the situation becomes clearer.

**Continue to take photos** on a daily basis, as below, to **monitor any growth or spreading of the rash**. Look over the rest of your body each day as a rash can also appear away from the bite site. Be mindful and aware of any other symptoms for the coming days/weeks/months remembering that **symptoms may have a delayed onset and fluctuate**. Keep a symptom diary and remember that resolution of the rash does not mean that the disease has been eradicated.



## Things to Tell Your Doctor

To help your doctor assess your case, it can be useful to make some notes covering what happened. For example:

- I spent the day in a park which had long grass and wooded areas.
- I found an embedded tick the next day and removed it. It was large and engorged.
- A week later I noticed a rash which started spreading (include photos if you took them).
- I then started to have headaches, neck stiffness, became light sensitive and felt like I had the flu (mention any other symptoms you are experiencing).

You may also wish to print a copy of the NICE guideline **here** so that you can have with you during the appointment, or direct your GP to the online **RCGP course** for medical professionals. Our **awareness animation** also covers key points on the diagnosis, testing and treatment of Lyme disease.

## Lyme Disease in Pregnancy

If you are pregnant and think you might have Lyme disease it is very important to seek medical attention, as there is a chance it can be transmitted to your unborn baby. You should be assessed and treated in a very similar way to someone who is not pregnant. However, you will be given a different antibiotic which is safe for pregnant women.

The NICE guideline says that it is unlikely that you will pass Lyme disease to your baby, however it is an area in which more research is needed.

Inform your maternity medical professionals and carefully monitor your baby for symptoms. Please bear in mind that symptoms can present differently in babies and can manifest as behavioural changes.

## Do Ticks Carry Other Infections?

It is important to remember that ticks can also carry other infections (**such as Babesia, Bartonella, Rickettsia, Erlichlia/Anaplasma**) in addition to Lyme disease. These are known as ‘co-infections'.

Additionally, the term 'co-infection' is sometimes used for opportunistic infections, which can take advantage of a suppressed immune system.

## Testing for Acute Lyme Disease

If you don't develop an EM rash but Lyme disease is suspected, then your GP will run a blood test. This is a two stage test whereby the second stage (Immunoblot test) is automatically completed if the first stage (ELISA test) is positive. The NICE guideline does state that if there are symptoms and a high suspicion of Lyme disease, **treatment should be started without waiting for a positive blood test result**. An example of this scenario would be a known tick bite and symptoms consistent with Lyme disease, but no rash.

It can take time for antibodies the tests search for to be produced and so any tests carried out soon after the bite may be negative, even if you are infected. Therefore, the NICE guideline recommends **another test around 4-6 weeks after the bite**. Steroid use or immunosuppression also increases the chance of a test producing a false negative result. Furthermore, the antibody response is variable and some people may never produce antibodies in measurable quantities. This does not mean they have not been infected.

If the first stage of the test is negative and symptoms continue beyond 12 weeks then your GP should request the second tier test, at which point they can also request for co-infections to be tested for. You can print off a request form and a manual for your GP **here.** The lab requires two copies of the form and the GP needs to write on it that they are requesting an Immunoblot and a full co-infection panel, 'due to clinical presentation of symptoms'. They also need to fully complete the sections of the form, which cover symptoms and risk. If they are unsure they can call the RIPL helpline for assistance. They should not refer you to the hospital for this. Results can take about 6 weeks. **Always request a copy of the results**. Occasionally, the NHS suggests a lumbar puncture to test a patient's spinal fluid. The accuracy of this test for Lyme disease is very low. However, if your doctor is recommending you have a lumbar puncture for another reason, it could be worth asking them to also test the spinal fluid for Lyme disease at the same time.

You can find a visual representation of the NICE testing recommendations **here.**

At any point, a doctor can begin treatment without a positive test result if there is clinical suspicion that you have been infected. It is vital to remember that we do not yet have a totally reliable test for Lyme disease and a negative test does not rule out Lyme disease. The NICE guideline evidence suggests that the test misses 1 in 5 cases, however this is from a small number of low quality studies and so it could miss far more. Regardless of the proportion which are correct, in the individual patient the test may or may not be correct. Additionally, we have no test that can tell us when the bacteria has been eradicated. Your doctor should never run a blood test after treatment to 'check the infection has gone'.

**To be clear you can have a negative Lyme test result and other normal blood test results and still be infected with Lyme disease.**

## Is Lyme Disease a Serious Illness?

Lyme disease can be an insidious infection. **We don't know why some people get very sick after an infected bite and why others don't**. It could in part be due to the strain of the Lyme bacteria or perhaps the mix of co-infections contracted at the same time. It could also be related to the strength of individuals' immune systems or their genetics. More research is needed.

**It is critical to catch any infection early**. Now is the time to be very vigilant and look after your health, including completing your treatment, eating well, staying hydrated, resting and reducing stress.

## Treatment for Acute Lyme Disease

The NHS will not normally provide prophylactic (preventative) treatment following a single 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 or 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**), as it is our experience that many doctors not familiar with the guideline under-prescribe. **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 as **if symptoms persist, you will require a second course of treatment and you do not want to delay this**. 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 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 important to note that **you can be reinfected with Lyme disease**. Having had the condition already does not make you immune.

**Your doctor should not repeat the blood test in order to ‘prove’ that Lyme disease has been eradicated as it is important that he or she is aware that we have no ‘test for cure’ and so the blood tests cannot be used as indicator that the infection has been eradicated.**

**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. Many Lyme-treating practitioners will advise that when on antibiotics you may also want to consider probiotics, ideally taken 2+ hours away from the antibiotic and for three times longer than the duration of the course of antibiotics e.g. a good quality, multi strain probiotic with a high CFU (the number of bacteria). You can find more information on taking doxycycline here.**

The NICE guideline says ‘do not routinely offer further antibiotics’ following two courses but 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** and so the specialist's role is likely to be ruling out other causes and providing support with symptoms rather than treatment of the disease.

## Lack of Awareness

When you go to your doctor it is important to know that many are unaware of the new NICE guideline and only a small percentage have taken the RCGP e-learning module on Lyme disease which was co-created by the charity Lyme Disease Action and the Royal College of General Practitioners. People are often told that ticks in their area don't carry Lyme disease. However, in reality, **Lyme disease is present all over the UK including in some urban parks and gardens**.

If you've been assessed by a GP but don't believe you are getting the appropriate care, it is worth asking whether your doctor has read the NICE Lyme disease guideline and whether they have passed the free elearning module on Lyme disease.

**You can ask for a second opinion** from a doctor who has passed the RCGP course if you do not feel you are being taken seriously. You can find a link to the RCGP Lyme Disease Toolkit **here**.

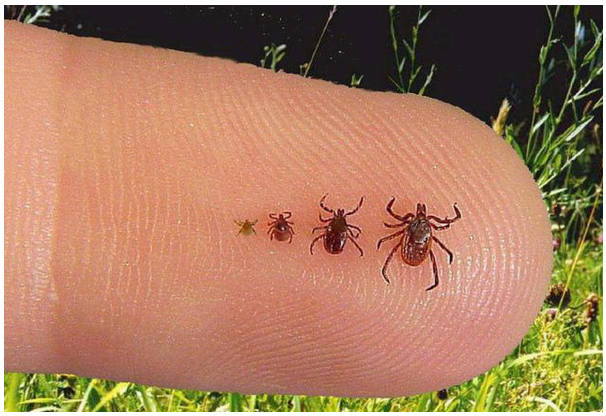
## What Can You Expect from an NHS Doctor for Acute Lyme Disease?

- ✓ 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 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.**

## Other Opinions On Acute Lyme Disease

It is important to be aware that some private Lyme doctors will recommend that patients take a course of antibiotics as a precautionary measure following a bite or a longer duration of antibiotics at a higher dose, but this course of action does not tend to be supported by the NHS. The US herbalist Stephen Buhner suggests a herbal protocol for acute Lyme disease, which is a natural alternative and **could be used for prophylactic treatment or in addition to antibiotics**. This can be purchased in the UK. This is considered alternative medicine and does not tend to be supported by the NHS.



## About Us

Lyme Disease UK is a registered charity (1182212) which exists to support people who are living with Lyme disease and looking for support and guidance. We are the largest patient support network in the UK and we have thousands of people in our Online Community on Facebook. LDUK is the most populated, virtual space for UK Lyme patients and their families.

We are stakeholders in the NICE Lyme disease guideline and commented extensively on its limitations. We also work with other Lyme organisations, politicians and journalists to raise awareness and push for change in the way Lyme disease is handled in the UK.

We have been approached by National Health Service trusts to give presentations, and we have also provided free awareness talks to schools, employers, outdoors organisations and the military. If you would like to organise a free awareness talk, please send an email to media@lymediseaseuk.com

Our aim is to ensure every UK resident infected gets the support they need.

## Further Information

Please see www.lymediseaseuk.com for more information.

You can sign up here to our newsletter, which also includes details of meetups around the UK.

If you want to learn to protect yourself from Lyme disease you can find out some prevention methods here.

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.

An education pack for children of all ages can be found here.

There have also been some books written on a wide range of aspects of Lyme disease. Links can be found here.

LDUK seminars with international Lyme disease practitioners can be found here.

To support our work you can make a donation here. Lyme Disease UK is grateful for all donations we receive, however big or small.

## Contact Us

Website: www.lymediseaseuk.com

Facebook Online Community: Lyme Disease UK Online Community

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