



# MANAGEMENT FILE

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This leaflet is based on an article which first appeared in the ME Association's quarterly *ME Essential* magazine. MEA membership costs £18 a year for people living in the UK/BFPO. For contact details, see foot of this page.



# LYME DISEASE: THE FACTS

## CONTROVERSIES AND UNCERTAINTIES

Lyme disease is a serious infection that is spread to humans by tick bites. It is always in the news – often because someone has not been diagnosed and treated during the crucial early stages. As a result, they may have developed a chronic and untreatable form of Lyme disease, which can cause joint, heart and neurological complications.

Lyme disease has a number of symptoms that are very similar to ME/CFS. So Lyme disease should always be considered if there is any indication that ME/CFS symptoms may have followed a tick bite, or were accompanied by an unusual skin rash at the site of a bite.

The term 'chronic Lyme disease' is now being used to describe a situation whereby a range of ME/CFS-like symptoms – fatigue, muscle and joint pain, cognitive dysfunction – are linked to Lyme disease, usually in the absence of a blood test confirmation.

Although Lyme disease is now recognised by most doctors as a genuine and potentially serious medical condition, there are controversies and uncertainties surrounding the diagnostic tests being used and the methods of treatment in both the NHS and the private medical sector.

This has led to increasing concern about the way in which some of the Lyme disease tests that are available overseas and in the UK private medical sector are providing an inaccurate diagnosis of 'chronic Lyme disease' and



the prescription of unnecessary courses of powerful antibiotics.

Lack of medical education about Lyme disease also means that late diagnosis and misdiagnosis are still occurring – just as with ME/CFS.

## WHAT IS LYME DISEASE??

Lyme disease is caused by a bacterial infection called *Borrelia burgdorferi*, which is spread by animal ticks. The ticks live in overgrown vegetation in woodland, heath areas and parks and feed on the blood of mammals – from where they pick up the infection. They attach themselves to mammals, deer in particular, and remain attached to the skin after a bite takes place.

Ticks don't jump or fly – but climb onto the skin if you brush against vegetation where they live. The bite is usually painless and may occur in hard-to-see areas of the body such as the groin, armpits and scalp. This is a highly effective way of spreading the infection

into the human blood stream. However, only a small proportion of ticks carry the bacteria – so being bitten does not automatically lead to being infected. And you're more likely to be infected where a bite remains attached for over 24 hours. So prompt and correct removal of the complete tick will significantly reduce the transmission of infection.

Tick bites are particularly common in areas of the UK where deer are present and the number of cases being reported is steadily increasing.

High-risk areas include Exmoor, the Lake District, the New Forest, the Yorkshire Moors and the Scottish Highlands.

Lyme disease is now being regularly reported from many other parts of Europe – from Southern Scandinavia down through northern Italy, and into Spain and Greece, and from the north eastern and north central parts of the USA. The commonest time of the year for being bitten is late spring through to early autumn.

# NHS BLOOD TESTS FOR LYME DISEASE



**A blood sample is tested for antibodies to the infection that causes Lyme disease. It takes the body two to three weeks to produce detectable levels of antibodies.**

The first antibody to be produced is called immunoglobulin M (IgM). The level of IgM increases over a period of about six weeks and then begins to decline.

Immunoglobulin G (IgG) antibodies are detectable several weeks after exposure. They increase to maximum levels at about four to six months, and may remain at high levels for many years.

The first blood test is an enzyme-linked immunosorbent assay (ELISA). The UK Health Protection Agency Lyme Borreliosis Unit uses one that detects both IgG and IgM antibodies to *B. burgdorferi*.

The ELISA is sensitive but has a high false positive rate, giving positive results in glandular fever, rheumatoid arthritis and other autoimmune conditions.

If the ELISA test is positive, an additional test called a Western blot is used to help confirm a diagnosis of Lyme disease. The UK Lyme Unit uses Western blots that test for IgM and IgG antibodies separately.

Another specific test, the polymerase chain reaction (PCR), detects the DNA (genetic material) of *B. burgdorferi*. This is used to confirm the presence of the infection in joint fluid in Lyme arthritis and in the cerebrospinal fluid in Lyme meningitis.

If you develop the characteristic spreading rash of Lyme Disease (erythema migrans) three to 30 days after a tick bite or possible exposure to ticks, your GP is highly likely to make a clinical diagnosis. You will be treated with antibiotics without having had any laboratory tests, and should make a complete recovery.

However, if you see your GP without a characteristic rash but with other symptoms that occur in early or later Lyme disease blood tests should be requested, particularly if you have had a recent tick bite or possible exposure to ticks in wooded or long grass areas.

If the ELISA test is carried out within a few weeks of a tick bite or possible exposure it may fail to detect antibodies to *B. burgdorferi*. It can be repeated a few weeks later. About 30% of tests are positive by two weeks and about 80% by six weeks. The rate increases with duration of infection until more than 99% are positive.

If the ELISA test is positive and both the IgG and IgM Western blot tests are negative, it is probable that the ELISA result is a false positive. So Lyme disease is not the cause of the symptoms.

If the ELISA and IgM tests are positive, with or without a positive IgG test, early Lyme disease is probable and treatment with antibiotics is advisable.

A positive ELISA test with a positive IgG and a negative IgM test can be seen in later Lyme disease. However, these results can also be seen when exposure to the infection took place a long time ago, and the current symptoms may be unrelated. This is particularly likely in

people who have been exposed to tick bites at work (like foresters), during recreation (like ramblers) or because they live near woodlands or heaths.

If you had been given antibiotics for any reason shortly after being infected, both the IgG and IgM responses might be greatly reduced or even absent.

## **Source: Lab Tests Online:**

Shortened link:

<https://tinyurl.com/y2srsvf2>

If a neurological infection is suspected then tests on the cerebrospinal fluid will be arranged.

In relation to the overlap with ME/CFS, analysis of cerebrospinal fluid from cases of neurological post treatment Lyme disease and people with ME/CFS has identified a range of proteins that appear to separate the two conditions (Schutzer et al 2013). Polymerase chain reaction testing is also available. This may be useful in testing joint fluid and biopsies of skin rashes.

The strength of the immune system response gradually declines during treatment. However, where there has been a very strong response, this can remain so – even after symptoms have cleared.

The Lyme disease service of Public Health England is provided by the Rare and Imported Pathogens Laboratory (RIPL) at Porton Down. Clinical staff are available to discuss more difficult cases with medical professionals during working hours on 01980 612348 or by email: [lyme.ripl@phe.gov.uk](mailto:lyme.ripl@phe.gov.uk).

The Gov.UK website provides more information and a P2 form that can be downloaded to request a Lyme disease test. Here's a shortened link to it: <https://tinyurl.com/yynzcbbp>



## WHAT ARE THE EARLY SYMPTOMS AND SIGNS?

Initial infective-type symptoms of Lyme disease include fatigue, fever, headaches, enlarged lymph glands, muscle pains (myalgia) and joint pains (arthralgia) – all of which are flu-like symptoms that could be consistent with the early stage of an ME/CFS-like illness.

There is often a very characteristic skin rash called erythema migrans at this stage. The rash, which usually appears between three and 30 days after being bitten, starts off as a red patch and steadily spreads out from the centre. It tends to appear at the site of the bite. As the edge of the rash expands the central part may start to clear – which is why it is sometimes called a bull's eye rash. There can also be fluid retention in the skin, vesicles and crusting. However, around a third of people do not develop this rash at all.

## COMPLICATIONS OF CHRONIC LYME DISEASE

Left untreated, Lyme disease can cause serious complications affecting the brain and nervous system, heart, joints and skin. These later features are divided into what are called early disseminated disease (affecting the nervous system) and late disease (affecting heart, joints and skin)

**Neuroborreliosis** is the name given to nervous system involvement, which occurs in about 10-15% of people. The symptoms tend to appear after several months but can appear earlier. They include paralysis of the cranial nerves causing damage to nerves supplying muscles in the face and a 'glove and stocking' loss of sensation in the limbs and meningitis.

**Lyme arthritis** is rarer in the UK than in the USA and can take years to appear. It tends to affect the knee and other large joints.

**Lyme carditis** is the name given to a rare complication affecting the heart whereby there is inflammation of the heart muscle (myocarditis), the sac surrounding the heart (pericarditis) and heart block.

**Acrodermatitis chronica atrophicans** is a rare skin complication that occurs in about 1% of cases in the more chronic stage. It initially consists of red patches on the extensor surfaces of the hands, feet, knees and elbows. Later on, the skin becomes thin and scaly – 'cigarette paper skin' – and is very difficult to treat.

## HOW IS LYME DISEASE DIAGNOSED?

Making a diagnosis of Lyme disease should be straightforward in someone who presents with typical symptoms and the very characteristic erythema migrans skin rash following a definite tick bite. Making a diagnosis where the clinical history is less certain, and with no evidence of a skin rash, can be far more difficult.

Diagnosis is assisted by the use of blood tests that look for evidence of an immune system response to the infection. These tests, which measure antibody levels, are available on the NHS and are briefly summarised below.

There are also various blood tests available from private laboratories in the UK and abroad. A great deal of controversy surrounds the value of some of these expensive commercial tests and they are not available on the NHS. We would not therefore advise people to rely on the results of these tests and to always go through NHS testing first.

## MISDIAGNOSIS OF LYME DISEASE

As already noted, there are very valid concerns about the way in which Lyme disease is being diagnosed and treated in some parts of the private medical sector.

A retrospective case note study of 115 adults with suspected Lyme disease, who were referred to one UK infectious diseases clinic, found that only a minority had Lyme disease. One third had ME/CFS. No specific diagnosis was made in approximately one third. And at least 53 unnecessary courses of antibiotics had been prescribed (Cottle et al 2012).

## HOW IS LYME DISEASE TREATED?

The good news is that this is an infection that is very sensitive to antibiotic treatment. So people who are diagnosed early on and promptly treated with antibiotics usually make a complete and rapid recovery.

However, if someone has more severe symptoms early on, then the response to antibiotic treatment can take much longer.

In straightforward early cases in adults, the National Institute for Health and Care Excellence (NICE) recommends the use of an antibiotic called doxycycline (100mg or 200mg once daily for 21 days). Alternative antibiotics include oral amoxicillin for 21 days or azithromycin for 17 days.

In the case of a clear history of a tick bite and characteristic rash, treatment should commence before blood test confirmation. NICE produces separate guidance for children based on age and weight. Women who are pregnant should also be treated with antibiotics.

Where symptoms persist, NICE recommends that other possible diagnoses be considered, the possibility of reinfection, and whether treatment was adhered to. If symptoms persist after two courses of antibiotics, advice should be sought from a specialist in Lyme disease or a reference laboratory.



## POST-TREATMENT LYME SYNDROME

About 10 to 20% of people with Lyme disease go on to develop chronic symptoms – this is known as post-treatment Lyme syndrome. Symptoms, which are very similar to those of ME/CFS, include debilitating fatigue, muscle and joint pain, and cognitive dysfunction.

Unfortunately, antibiotic treatment at this stage is not usually helpful. Some people with post-treatment Lyme syndrome will improve or recover over time. But others do not.

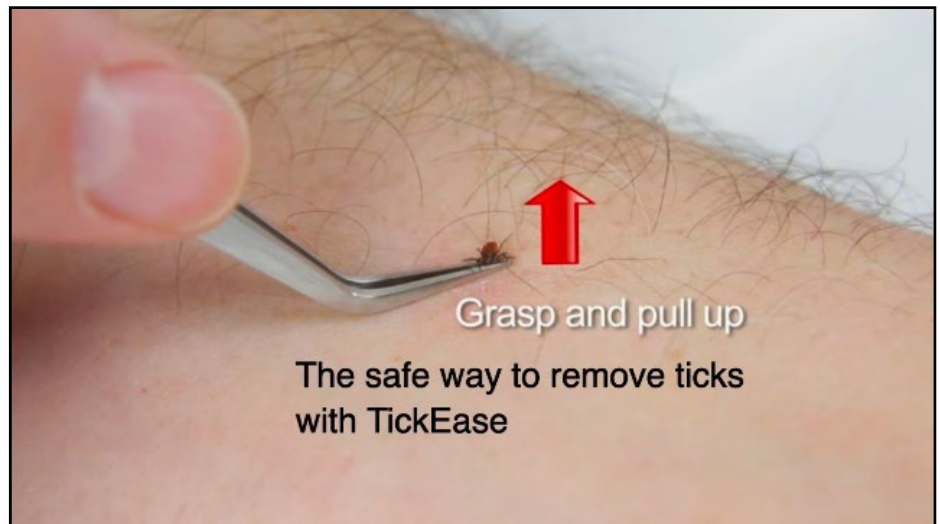
## CHRONIC LYME DISEASE

Controversy and uncertainty surrounds both the diagnosis and treatment of people with ME/CFS-like symptoms but no clear laboratory evidence of Lyme disease. It's possible, as with ME/CFS, that the infection has cleared but there is persisting overactivity of the body's immune system.

## FURTHER INFORMATION

The American Centers for Disease Control and Prevention website has a list of frequently asked questions about Lyme disease:

<http://www.cdc.gov/lyme/faq/>



## PREVENTING AND REMOVING TICK BITES

- Avoid long grass and dense overgrowth when out walking
- Wear appropriate clothing when out of doors in high risk areas: Long trousers tucked into socks, shirts tucked into trousers.
- Use an insect repellent on exposed skin: Lemon eucalyptus oil has been shown to be very effective at repelling tick bites. DEET is also effective.
- Check for ticks every day on yourself, and on pets, if you are out and about in a high risk area .
- Remove ticks promptly: Pull the tick out steadily (without twisting or jerking) by gently gripping it as close to the skin as possible with fine-tipped tweezers or a commercial tick removing device. There is no evidence that smothering the tick in petroleum jelly or burning with a lighted match are effective. Afterwards apply an antiseptic cream to the skin.
- Inexpensive tick removal devices are useful if you regularly visit woodland. They can be purchased from vets, pet shops and internet suppliers.

## MEDICAL REFERENCES

- Centers for Disease Control and Prevention press release (19 August, 2013). CDC provides estimate of Americans diagnosed with Lyme disease each year. URL shortened to: <https://tinyurl.com/y7v6qfb3>
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**Medical information contained in this leaflet is not intended to be used as a substitute for medical advice or treatment from your own doctor.**

**The ME Association recommends that you always consult your own doctor or healthcare professional about any specific problem.**

**We also recommend that any of the medical information provided by The MEA in this leaflet is, where appropriate, shown to and discussed with your doctor.**



# ME CONNECT

The Support and Information Service for people affected by ME/CFS/PVFS and Long Covid



# Freephone 0808 801 0484

For opening hours visit:  
[meassociation.org.uk/me-connect](https://meassociation.org.uk/me-connect)

Contact ME Connect  
**3 WAYS TO GET IN TOUCH:**  
by phone, email  
or social media private message



## HERE TO LISTEN

We are here to listen, validate and empathise with any issues you might be facing.



## VITAL SUPPORT

We are here to help you reach an informed decision.



## SAFE ENVIRONMENT

We provide a safe, confidential and understanding environment where you can be heard and understood.

*We're here for you!*



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