
Aches, pains and fatigue - could it be Lyme disease?



Lyme Resource Centre (LRC) is a charity with a mission to minimise risk of Lyme disease whilst enjoying the outdoors, by educating the public and health professionals about ticks and Lyme disease.

LIZ MURRAY

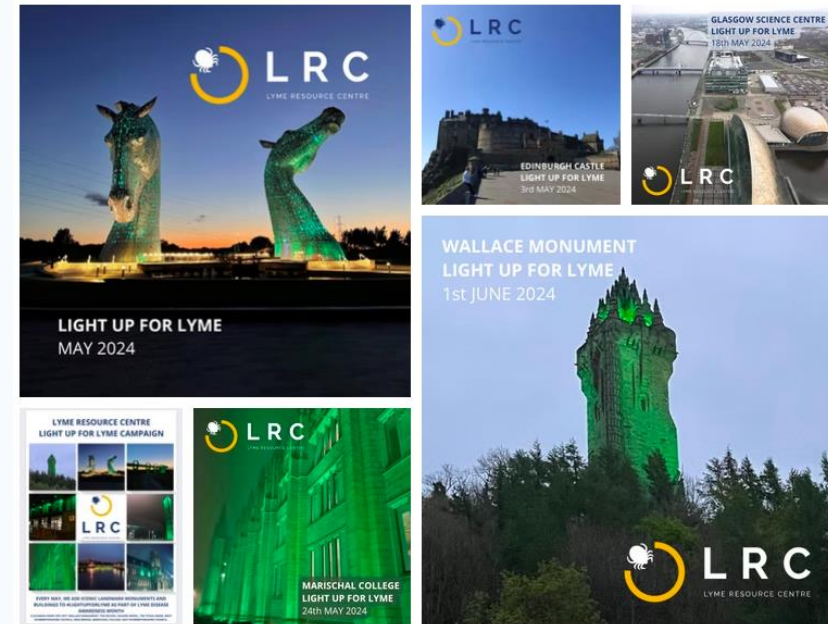
TRUSTEE, LYME RESOURCE CENTRE

Lyme Disease Awareness Month



- Lyme Disease Awareness Month is observed internationally every **May**, especially in countries where Lyme disease is common.
- It is dedicated to raising awareness about Lyme disease, its symptoms, and the importance of tick bite prevention.

Light up for Lyme



Ticks and Lyme disease – a growing issue

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- Ticks have increased in number and have a wider distribution over time
 - This presents a public health risk as ticks can transmit Lyme disease, other tick-borne infections
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- Increased potential for human encounters with ticks due to
 - changes in wildlife populations, habitat modification
 - changes in human behaviour (e.g. spending time outdoors, outdoor activities)
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- Since data collection began (2005), there has been a gradual increasing trend in cases of Lyme disease

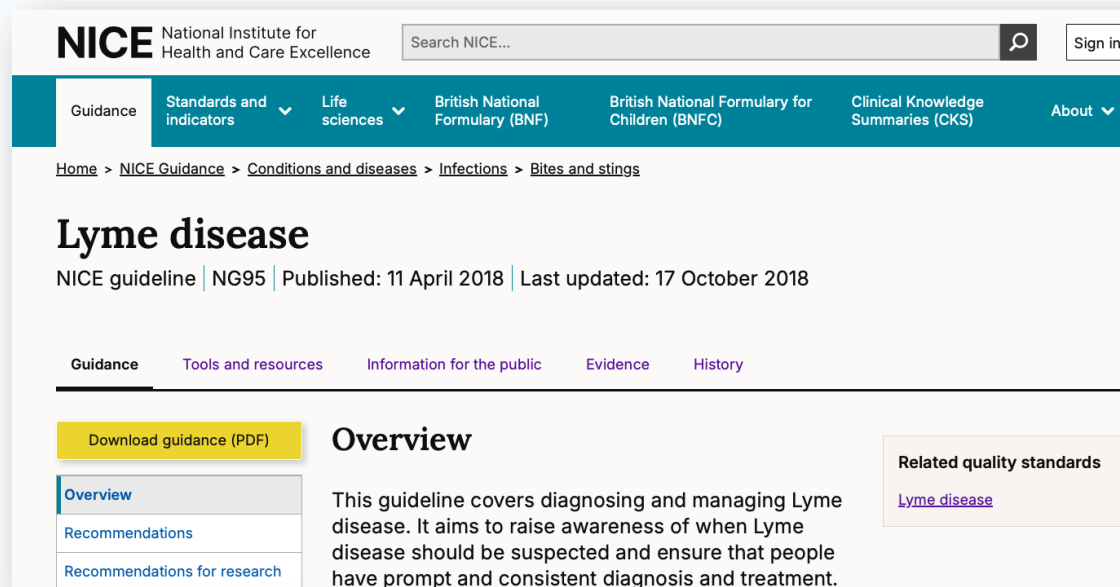
But awareness, understanding is poor

54%

were not aware of need to protect against tick bites prior to illness*

63%

were not aware of the signs / symptoms of Lyme disease prior to illness*



of 80% who had difficulty accessing treatment

90%

said lack of disease awareness, expertise of health professionals was key barrier*

Aches, pains and fatigue - could it be Lyme disease?

DEENA JANE DEAN

ADVANCED PRACTICE PHYSIOTHERAPIST

MAY 2025

Contents

- What is Lyme disease?
- Where ticks exist
- Early symptoms
- Late symptoms
- How to distinguish from other conditions
- Case study
- What to do if you suspect Lyme disease
- Tests
- Treatment
- Prevention
- Where to signpost patients to

What is Lyme disease?

- A bacterial infection carried by ticks worldwide
- It causes a variety of symptoms including joint, muscle, nerve pain and fatigue
- It's named after a town in America - 'Old Lyme'
- Discovered after a large number of children were diagnosed with juvenile rheumatoid arthritis
- Risk of tick bites can be throughout the year, when the temperature is above 7 degrees centigrade
- Ticks can be as small as a pin head
- Tick bites are painless and easily go unnoticed



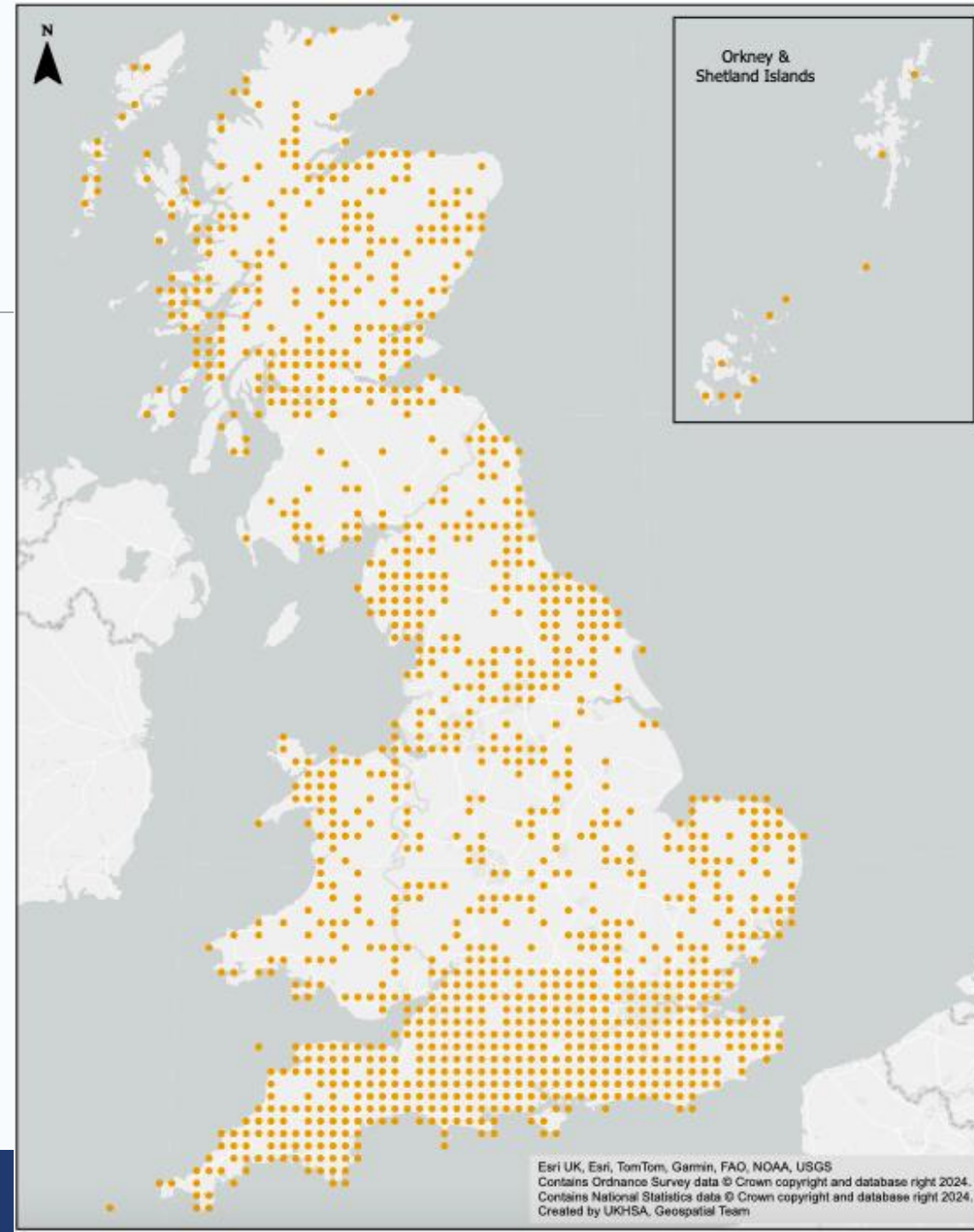
What is Lyme disease?

- Ticks can be found in woodland, countryside, parks, forests and gardens
- On average between 5-10% of ticks in the UK carry *B. Burgdorferi* (the bacteria causing Lyme disease)
- There is NO proven minimum time a tick needs to be attached before Lyme disease can be contracted
- UKHSA estimates 2-3,000 case per year but real incidence is unknown, probably at least 3x that level
- Ave Seroprevalance for *B. Burgdorferi* in English adults 0.49% [1% in the SW] (Hart et al, 2025)
- Seroprevalence for Scotland estimated as **4.2%** but with regional variation [0-8.6%] (Munro et al 2015)

Distribution of *Ixode ricinus* across Great Britain

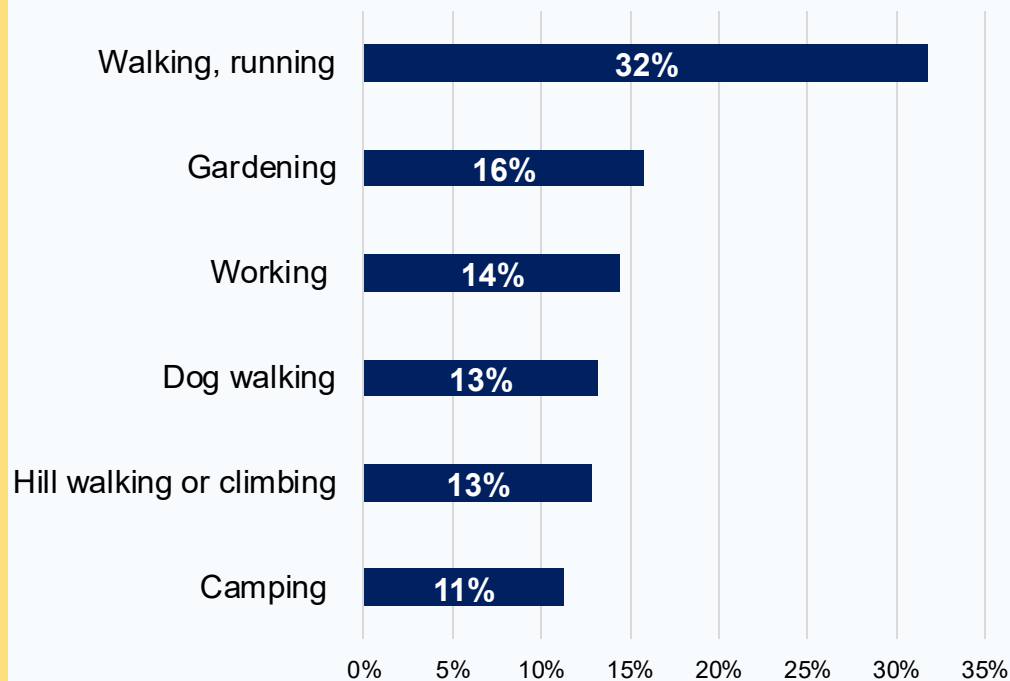
UKHSA Tick Surveillance Scheme (at July 2024)

<https://assets.publishing.service.gov.uk/media/667bf5f75b0d63b556a4b391/Tick- Ixodes-ricinus -distribution-map-for-England-Scotland-and-Wales.pdf>

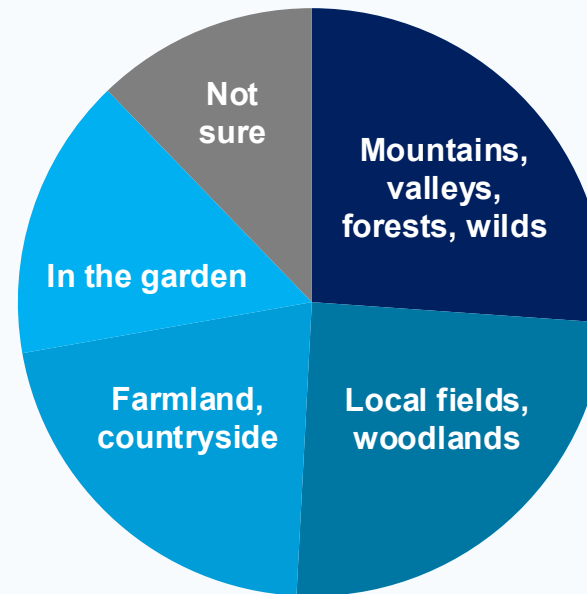


Tick bites occur in everyday places & doing everyday activities

Top activities when bitten



Top 5 locations when bitten

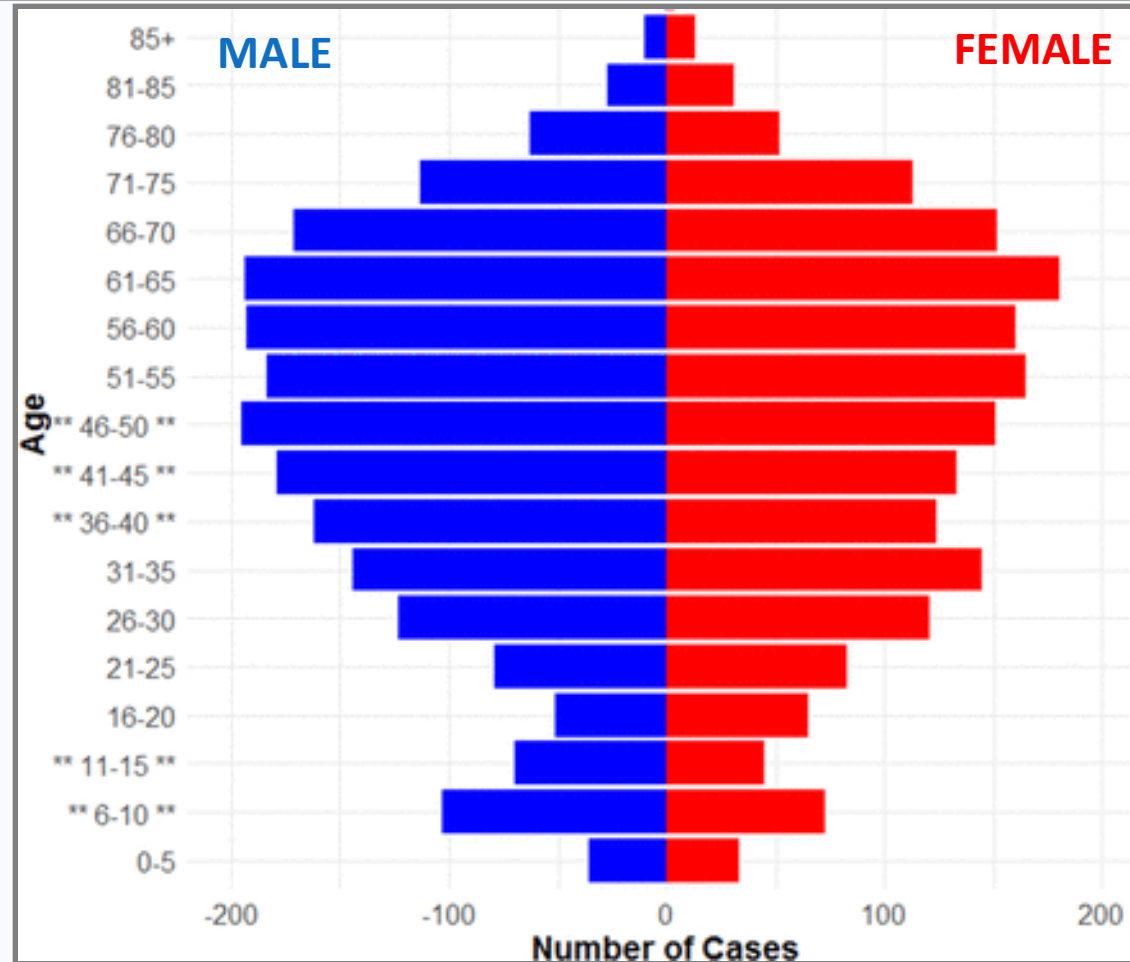


Where bitten in UK

83%
respondents reported
being bitten at sites
within the UK

Remaining
17%
were bitten outside
the UK or were
unsure of the location

Who gets Lyme disease?



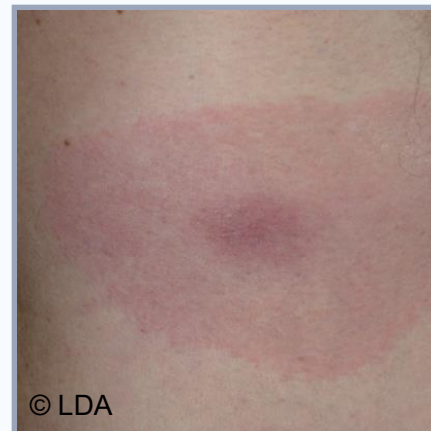
Population demographics of laboratory-confirmed Lyme disease cases in England and Wales, 2013 – 2016. (Tulloch et al)

Early symptoms

- These occur days-weeks after the infected tick bite.
- Erythema Migrans (EM), Bullseye (or other appearances) around the tick bite.
- The rash can show in other areas of the body away from the tick bite area.
- The rash is diagnostic; therefore, no tests are needed and the patient should be treated for Lyme disease by the GP.

Erythema migrans

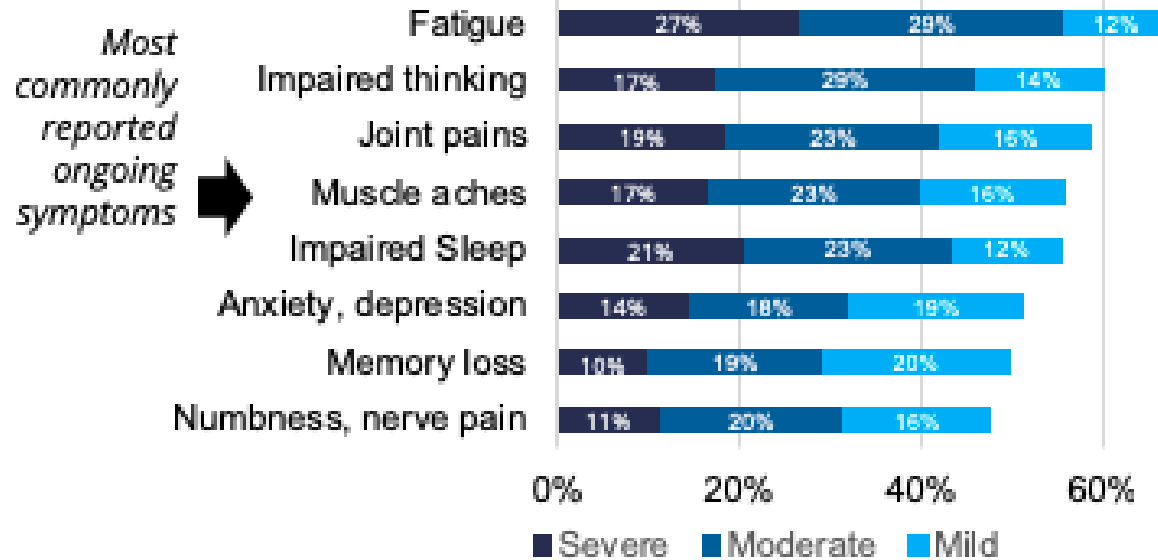
Images from NICE Guideline (NG95)



Persistent symptoms

78%
have ongoing
symptoms

44%
been unwell for
6+ years



"I was fiercely independent and strong before, now I'm vulnerable and rely on others goodwill and love. I lost career, family, friends, income, independence. It's hard to do anything now.....I wouldn't wish this on anyone."

THESE ARE THE PATIENTS WE WILL SEE, WHEN IT GETS HARDER TO DIAGNOSE!

- Late symptoms occur months to years after the tick bite.
- Masquerades as an MSK condition.
- A third of people with Lyme disease do not develop a rash and may not be aware of the tick bite.
- These symptoms may have been preceded by a flu like illness 'the summer flu', approx. 3-4 weeks after the tick bite.
- Other signs are - facial nerve palsy, uveitis.

Disseminated Lyme disease

Weeks, months or years after becoming infected; multi-systemic, fluctuating, migrating symptoms

Neurological (Neuroborreliosis)

- Facial palsy
- Motor & sensory neuropathies
- Neuropathic pain
- Cognitive disorders
- Dizziness (gait/ balance)
- Hyperacusis / visual disorders
- PoTS (dysautonomia)

Cardiovascular

- Arrhythmias (risk of cardiac arrest)
- Pericarditis
- Myocarditis
- Vasculitis

Musculoskeletal

- Arthralgia / arthritis
- Myalgia / myositis
- Tendonitis
- Bursitis

Dermatological

- Erythema migrans (single or multiple)
- Acrodermatitis chronica atrophicans (ACA)
- Borrelia lymphocytoma

Psychiatric / Psychological

- Anxiety
- Depression
- Psychosis
- Suicidal ideation

General

- Fatigue
- GI symptoms
- Sleep disorders (disrupted circadian rhythm)
- Ophthalmic (uveitis, scleritis, visual changes)

How to distinguish between other conditions



Mis-diagnoses

NEUROLOGICAL

- Bell's palsy
- MND
- Parkinson's Disease
- Chronic Pain
- Dementia
- FND

OTHER

- Arthritis
- Ehlers Danlos syndrome
- PMR
- Long covid
- SLE

Lyme disease is described as '*the new great imitator*', as it mimics many other conditions

- Symptoms can be migratory - 'the pain moves'.
- There is no diurnal pattern.
- Movement does not help / rest doesn't make worse.
- Ongoing rashes can occur but are rare and not linked with photosensitivity.
- Not linked with oral ulcers or Raynaud's disease.
- If a person has rarely contacted their GP, but then has frequent consults with these vague symptoms, that should ring alarm bells.

Case study

- 46 year old male, fell runner and ultra marathon runner.
- No PMH, no DH, infrequent contact with GP surgery.
- 2 month history of lack of energy and multiple joint and muscle pains
 - especially headaches, jaw, neck and hands.
- All worsening, no diurnal pattern.
- GP performed bloods
 - TFT, LFTs, Glucose, Ferritin, U+E all normal
 - FBC > slightly low lymphocytes
- Due further bloods when patient remembered a tick bite 3 months prior to this whilst on Isle of Mull.
- Vit, D, ESR, Iron studies and B.burgdoferi added to tests
- Positive for Lyme disease.

What could have happened....



A word cloud featuring various health and wellness practices. The words are arranged in a circular pattern, with 'Physiotherapy' and 'Diet' being the largest. Other prominent words include 'Counselling', 'Acupuncture', 'Herbals', 'Reflexology', 'Nutritionist', 'Massage', 'Biomagnetic-Therapy', 'Yoga', 'Osteopathy', 'Infrared-Sauna', 'Hypothermia', 'Fluorescence', 'Lymphatic-Massage', 'Cold-Therapy', 'Exercise', 'Psychology', 'Medical-Herbalist', 'Functional-Medicine', 'Craniocervical-Therapy', 'Chiropractor', and 'Oxygen-Therapy'. The words are in various shades of blue and black.

Physiotherapy

Diet

Counselling

Acupuncture

Herbals

Reflexology

Nutritionist

Massage

Biomagnetic-Therapy

Yoga

Osteopathy

Infrared-Sauna

Hypothermia

Fluorescence

Lymphatic-Massage

Cold-Therapy

Exercise

Psychology

Medical-Herbalist

Functional-Medicine

Craniocervical-Therapy

Chiropractor

Oxygen-Therapy

What to do if you suspect Lyme disease

Ask relevant clinical questions: get a good timeline of when symptoms started.

- Had they been on holiday in the weeks/months prior to symptoms starting
 - type of holiday (e.g. camping)
 - location (e.g. in a high at-risk area (like Scottish Highlands / Islands, New Forest)).
- At risk occupation (farmer, vet, military, forestry etc.).
- At risk recreation (walker, runner).
- Ask about a "summer flu".
- Ask about facial palsy.

Suspecting Lyme disease

- Request bloods (borrelia burgdorferi test) BUT ensure the patient and GP are aware of the low sensitivity (i.e. false negatives).
- Blood tests taken within 4-6 weeks of a tick bite may be unreliable
- Most Lyme disease is diagnosed by a GP BUT *80% of people, family / friends had a suspicion of Lyme disease when seeking help.
- *22% of people had a diagnostic delay of over 5 years.

Testing

- Tests should be part of overall clinical assessment; **negative test does not exclude Lyme disease**
- Testing looks for antibodies made as a response to the infection.
- Antibodies can last for years so cannot be used to measure a 'cure' but do NOT give immunity to further infected tick bite.

Treatment

- NICE guideline
 - 3 weeks of either Doxycycline, Amoxicillin
 - Azithromycin for 17 days.
- May cause the person to be unwell (Jarisch-Herxheimer reaction) within the first few days due to the death of large numbers of bacteria.
- Can give a second course of Antibiotics
- Test can take 2 weeks to come back, guidelines state treatment can commence whilst awaiting results.

Note

- There is no international consensus on diagnosis or treatment
- Some USA guidelines advise treating until symptoms resolve

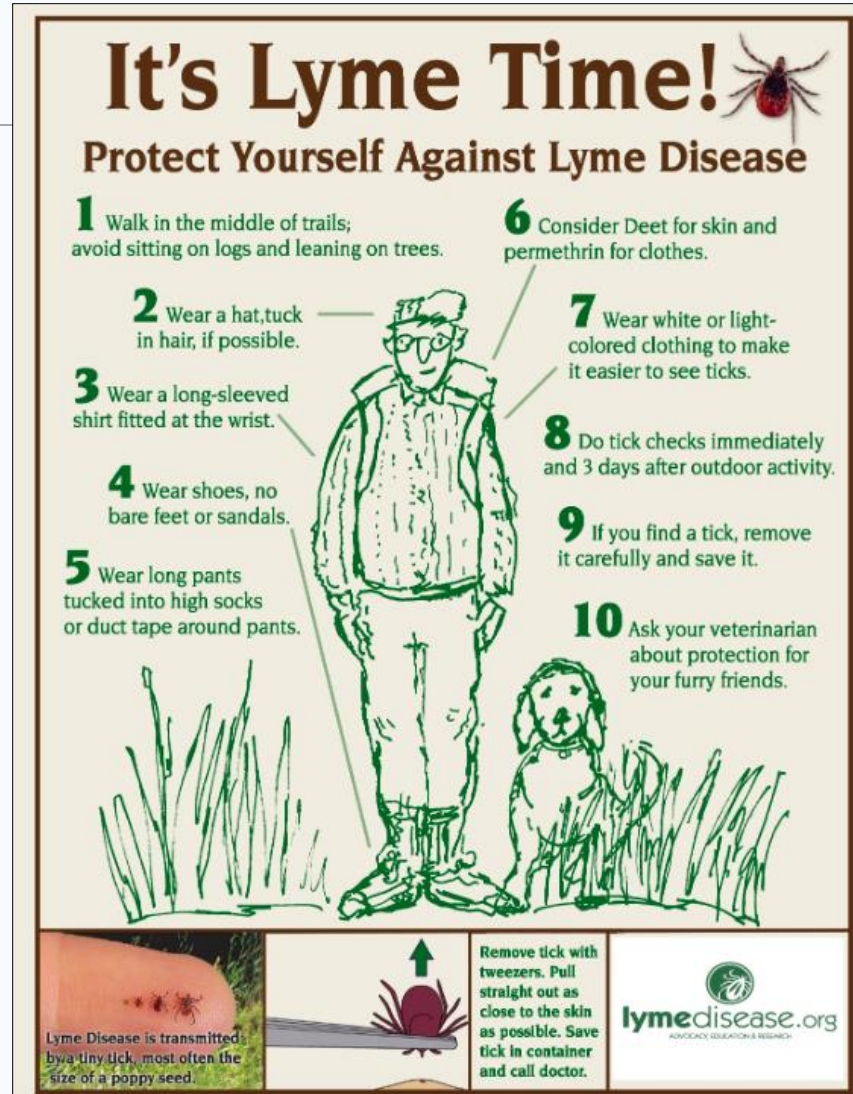
NICE Guideline (NG95)

Acknowledged limitations

- Lack of robust epidemiological data on Lyme disease in UK population
- Poor-quality evidence on diagnosis and treatment
 - Testing has limitations (false negatives) - clinical judgement required
 - There is a need to develop diagnostic tests appropriate for UK infections
 - Evidence on effectiveness of antimicrobial regimens is poor quality, out-dated, from small studies
 - Effectiveness of extended or re-treatment regimes remains uncertain
- **Better evidence may improve diagnostic and treatment decisions**
- **Recommendations aim to standardise antibiotic treatment**

Tick Bite Prevention - prevention is better than cure!

- Keep skin covered
- Wear long sleeves, tuck trousers into socks
- Wear light-coloured clothing
- Use an insect repellent
- Keep to paths - avoid long grass
- Carry a tick removal tool
- Check for ticks during and after being outdoors
- Check children and pets for ticks.
- Remove any attached ticks carefully
- Know, watch out for the signs and symptoms of Lyme disease



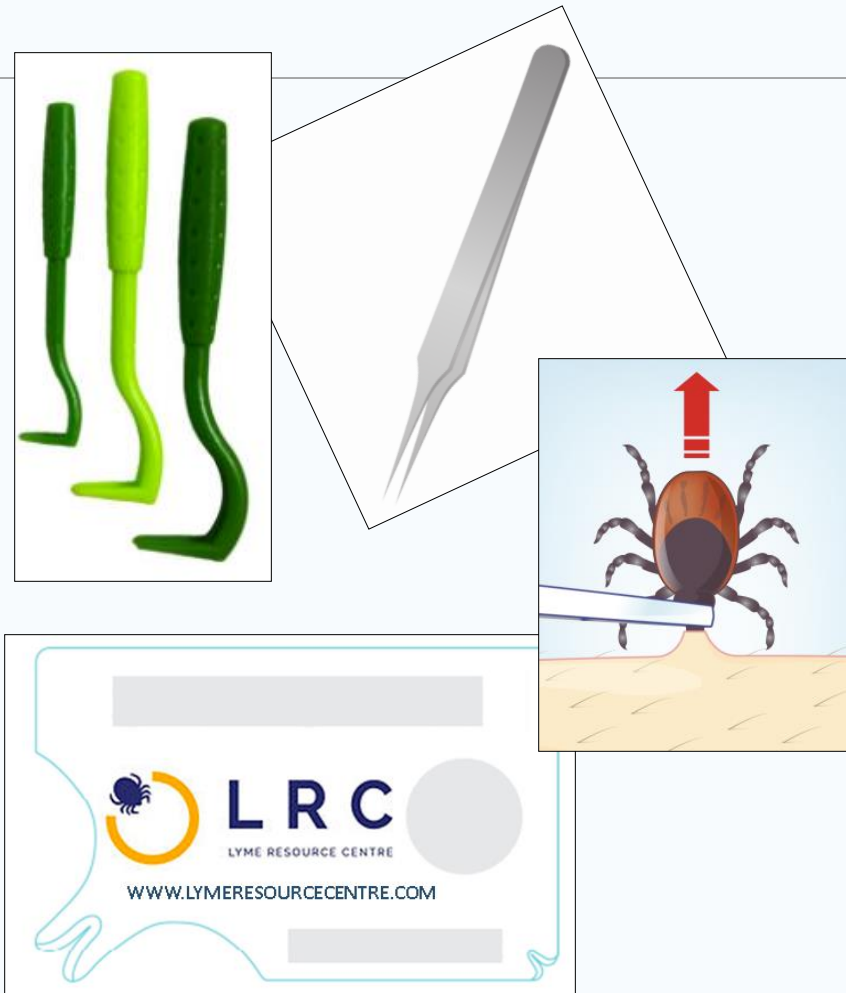
In Lyme Resource Centre's Lyme Disease Experience Survey* (2024)

- **62%** not aware of need to protect against tick bites prior to illness
- **69%** not aware of signs and symptoms of Lyme disease prior to illness
- **33%** did not remember a tick bite

Removing a tick

✓ DO

- Take a picture of the tick
- Remove it carefully, ASAP - longer attachment increases risk of infection
- Use tick removal device - a card remover or tick twister - following the instructions
- OR use specialist fine-pointed tick removal tweezers; hold them parallel to the skin to lift tick
- Clean area with antiseptic or soap and water
- Consider keeping tick in a bag in freezer in case it needs to be tested later



DON'T X

- Try not to do things that distress the tick during removal – it increases the risk of transmitting infection
- Do not cover tick with substances such as gels, oils, alcohol or try to burn it
- Don't squeeze body of the tick when removing it
- Don't use normal / broad tipped tweezers

Where to sign post patients to

Lyme Disease Resource Centre <https://www.lymeresourcecentre.com/>

Lyme Disease UK <https://lymediseaseuk.com>

RCGP Lyme Disease toolkit

<https://elearning.rcgp.org.uk/mod/book/tool/print/index.php?id=12535>

Take home messages

- In patients with vague widespread symptoms that aren't MSK in nature, Lyme disease should be a possible differential diagnoses.
- Ask about - occupational risks, recreational risks, holidays to high risk areas, flu symptoms, pins & needles, numbness, facial palsy.
- Get a detailed timeline of symptoms, not being aware of a tick bite ***does not*** exclude a possible Lyme disease.
- Request testing, giving a good rational.
- Signpost the patient to resources so they can advocate for themselves if needed.

Key resources, references

- Lyme disease | Guidance | NICE <https://www.nice.org.uk/guidance/ng95>
- Lyme disease | Health topics A to Z | CKS | NICE <https://cks.nice.org.uk/topics/lyme-disease/management/>
- Lyme Disease Toolkit | RCGP Learning <https://elearning.rcgp.org.uk/course/view.php?id=1157>.
- Summary of Lyme Disease | RCGP Learning <https://elearning.rcgp.org.uk/course/info.php?id=164>
- Lyme disease – UK Health Security Agency <https://ukhsa.blog.gov.uk/2024/03/21/what-is-lyme-disease-and-why-do-we-need-to-be-tick-aware/>
- Lyme Resource Centre <https://www.lymeresourcecentre.com/>
- Lyme Disease UK <https://lymediseaseuk.com/>
- Lyme arthritis: It's never too late for joint decision making
<https://www.sciencedirect.com/science/article/pii/S2590170224000669>
- Seroprevalence of *Borrelia burgdorferi* sensu lato antibodies in English adult blood donors: A nationwide cross-sectional study, 2021–2022. [Ticks and Tick-borne Diseases](#), [Vol 16, Issue 1](#), 2025

A charity with a mission to minimise risk of Lyme disease whilst enjoying the outdoors, by educating the public and healthcare professionals about ticks and Lyme disease.



Outdoor awareness signage



Resources for schools & youth organisations



Awareness posters & leaflets

Questions?

