Recognising the signs and symptoms of Lyme disease - ‘The New Great Imitator’

May 2025, Primary Care Show

LRC

LYME RESOURCE CENTRE

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 challenge

- 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

- 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)

- Since data collection began (2005), there has been a gradual increasing trend in cases of Lyme disease

Adapted from UKHSA https://ukhsa.blog.gov.uk/2024/03/21/what-is-lyme-disease-and-why-do-we-need-to-be-tick-aware/

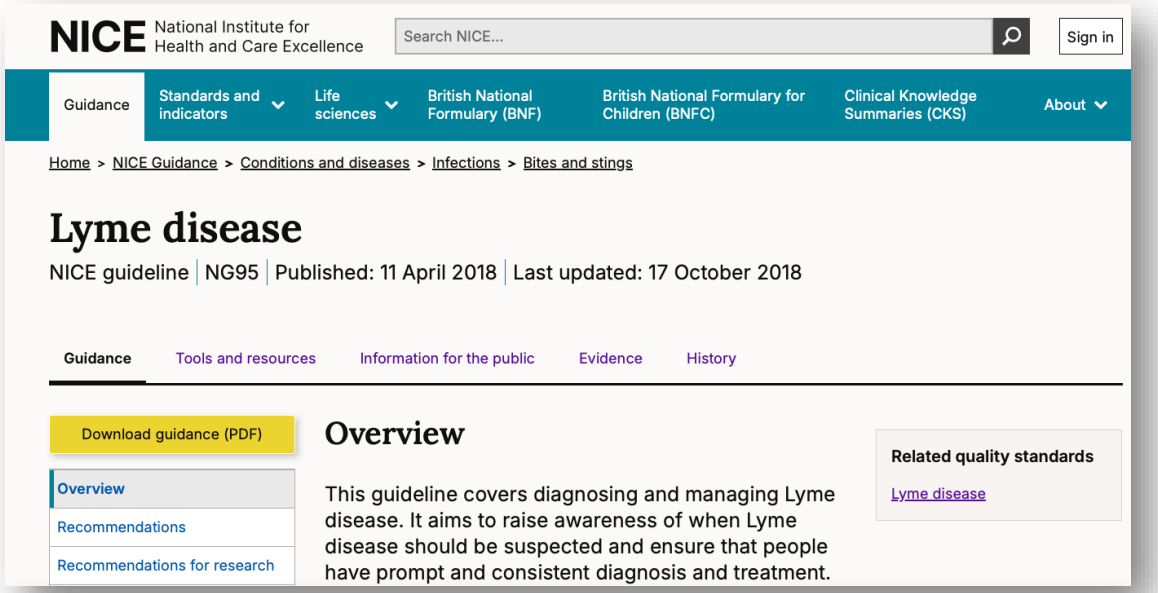
Yet awareness, understanding is poor

64%

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

69%

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



of 83% who had difficulty accessing treatment

90%

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

*Lyme Resource Centre - Lyme Disease Experience Survey (n=475), 2024

Recognising the signs and symptoms of Lyme disease - 'The New Great Imitator'

Kate Lawlor, RGN (retired)

May 2025, Primary Care Show

Session Objectives

During this session we will cover

- Recognising the signs and symptoms of early and disseminated Lyme disease
- Differentiating erythema migrans rashes from other insect bites or skin conditions
- Understanding the importance of early and adequate antibiotic treatment in preventing persistent Lyme-related symptoms
- Where to access clinical guidelines on Lyme disease
- Confidently advise on tick bite prevention and the correct use of tick removal tools

What is Lyme disease?

- An infectious disease caused by the bacterium Borrelia burgdorferi, a spirochete
- Vector-borne zoonosis
- Transmitted by the bite of an infected tick
- Most common tick-borne disease in Europe & North America

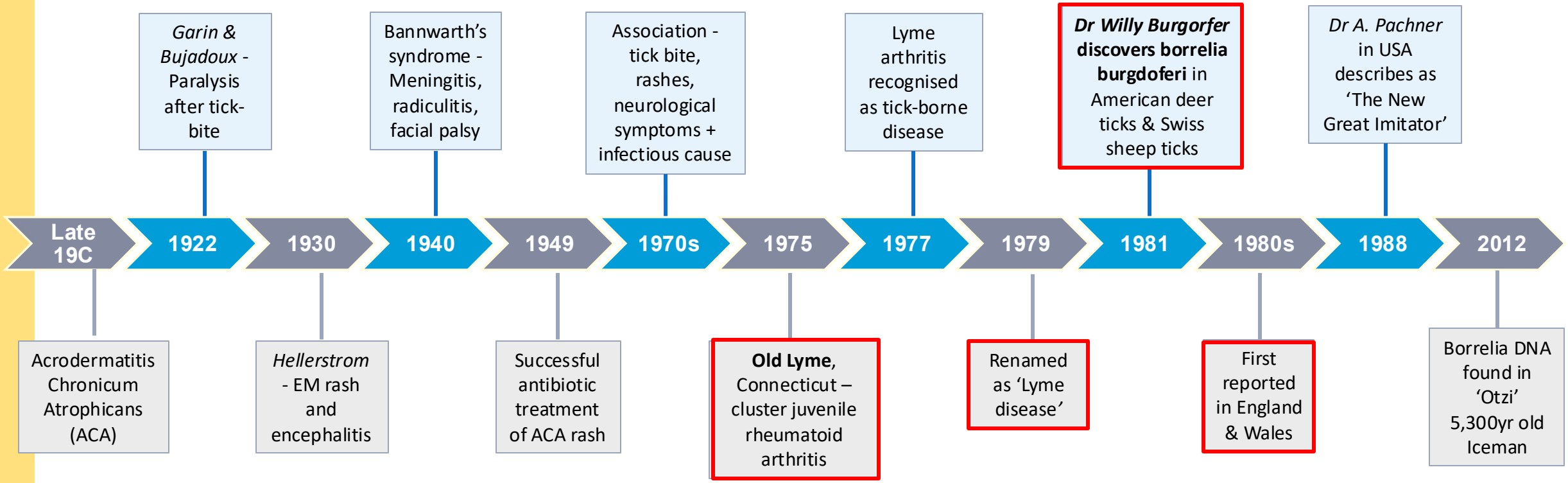
Borrelia burgdorferi sensu lato complex has multiple genospecies

- Borrelia burgdorferi sensu stricto (USA) - Lyme arthritis
- Borrelia garinii (Europe & Asia) - neurological presentations
- Borrelia afzelii (Europe & Asia) – skin, neurological presentations

- *Can spread quickly around the body*
- *Is attracted to skin, nerves, joints, cardiac tissue, eyes*
- *Can hide from & disrupt the immune system*

Brief History: Europe & USA

- Symptoms of Lyme disease have been recognised in mainland Europe for > 100 years
- Evidence bacteria has been present in North America for > 60,000yrs



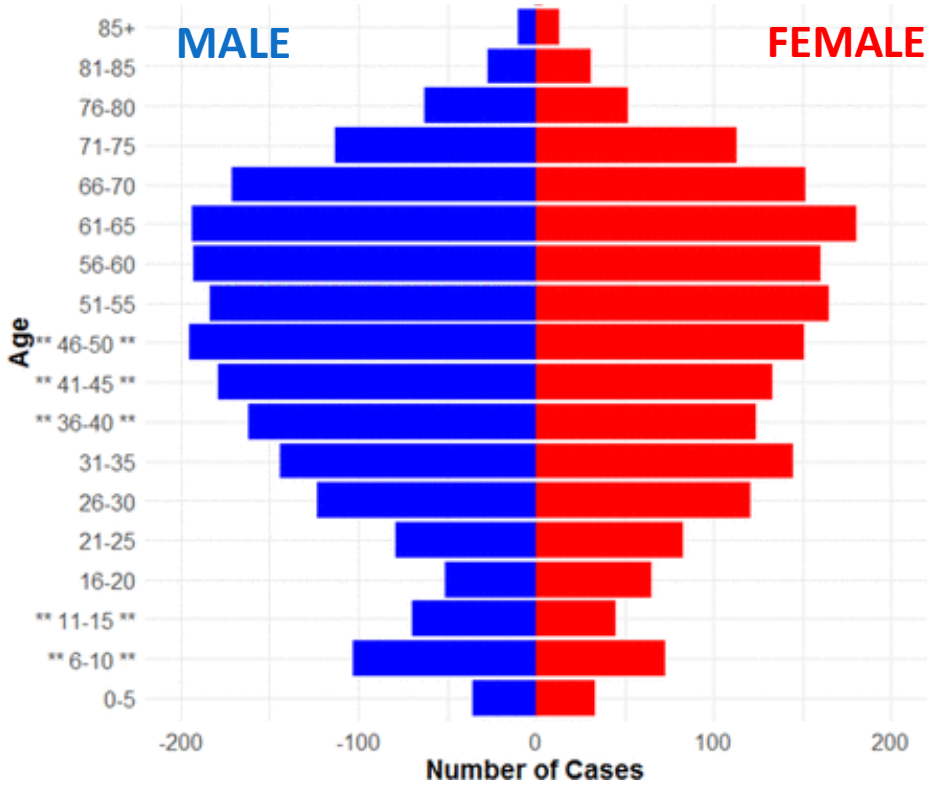
Incidence, seroprevalence & demographics

Estimated annual population incidence of Lyme disease (no standardised data collection methods)

Country	No. Lyme Cases
USA	476,000
France	50,000
Germany	50,000-60,000
UK	2000-3000

- Lyme disease not notifiable in UK
- Only lab confirmed +ve blood tests recorded
- Lab-confirmed figures under-estimate true incidence

- Global B. burgdorferi sensu lato seroprevalence estimated as **14.5%** (BMJ Glob Health. 2022; 7(6). Dong et al)
- Seroprevalence for Scotland estimated as **4.2%** but with regional variation [0-8.6%] (Seroprevalence of Lyme borreliosis in Scottish blood donors Transfus Med 2015; 25(4) Munro et al)
- Average English adult population exposure to *Borrelia burgdorferi* based on blood donor samples estimated at 0.49 % [< 1% in SW England]. (Hart et al, Science Direct, January 2025)
- Study in NHS Highland; incidence vs laboratory reported cases - Read codes indicate **2.1x higher**; patients treated **5.2x higher** (Incidence & management of Lyme disease: a Scottish general practice retrospective study, Mavin et al BJGP Open 2024



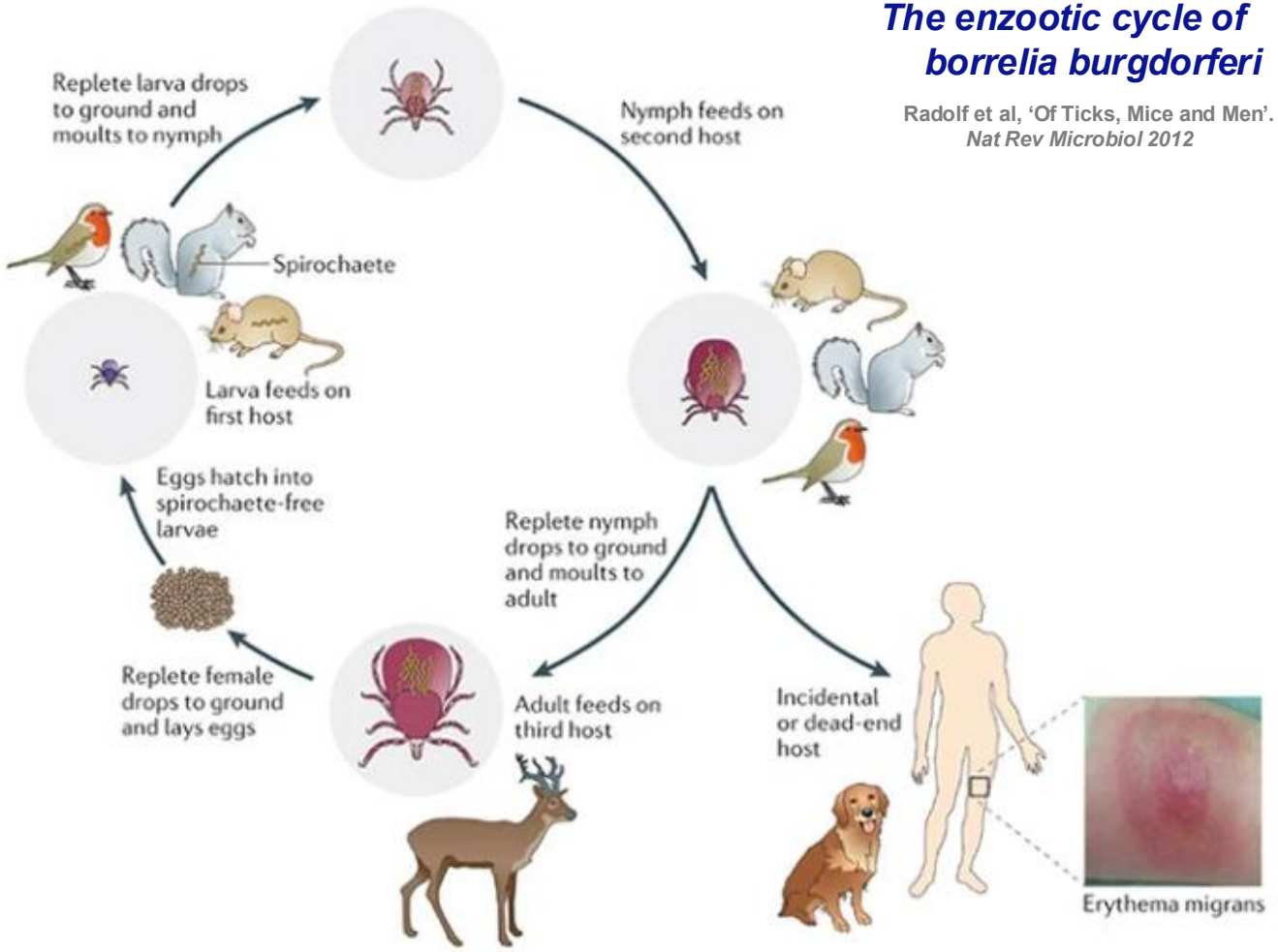
Population demographics of laboratory-confirmed Lyme disease cases in England & Wales, 2013 – 2016
(Tulloch et al)

About Ticks

Small blood sucking arthropods (related to spiders, mites); found in moist shady areas (e.g. woods, heath, moorland, parks, gardens carried in to houses); cannot fly or jump

The enzootic cycle of borrelia burgdorferi

Radolf et al, 'Of Ticks, Mice and Men'.
Nat Rev Microbiol 2012



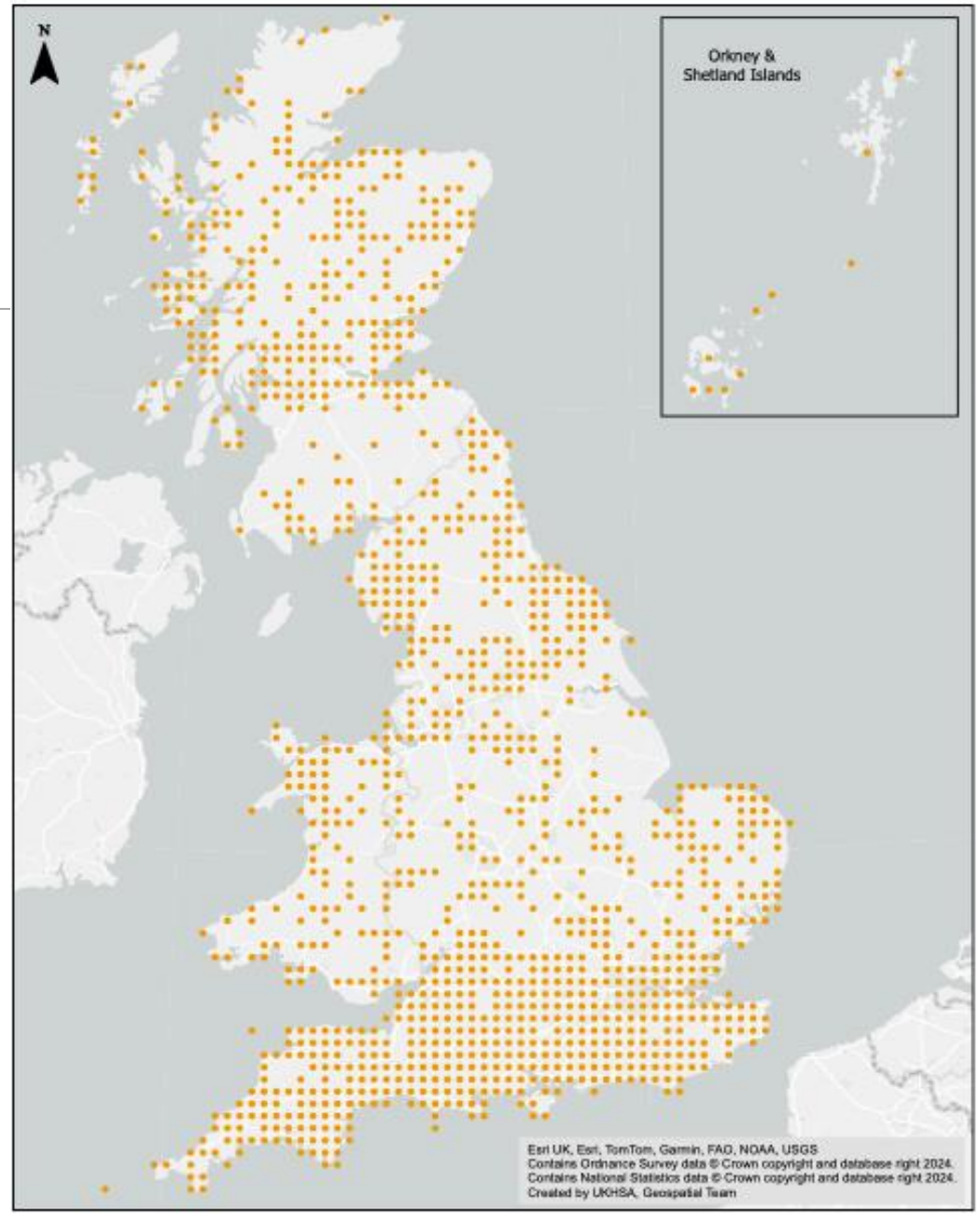
UK Ticks

Sheep tick	*Ixodes ricinus*
Hedgehog tick	*Ixodes hexagonus*
Fox/Dog tick	*Ixodes canisuga*

UK Ticks – where are they?

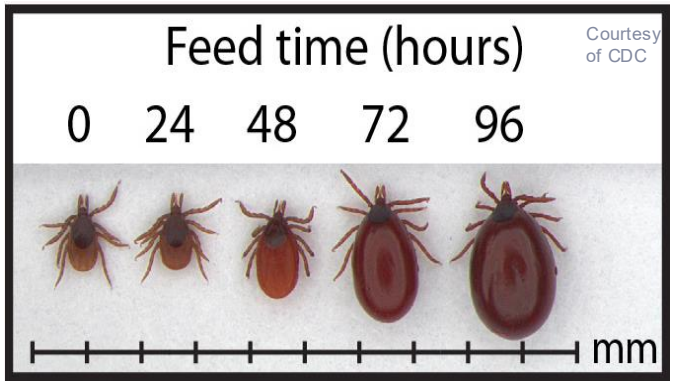
- UK Health Security Agency (UKHSA) carries out a tick surveillance programme
- Public encouraged to report, send ticks to UKHSA
- Key message - **ticks are everywhere**
- Known regional hot spots (e.g. Scottish Highlands, New Forest)
- Local hot spots also exist (e.g. a local park)
- 10-15% tick bites acquired abroad

Distribution of Ixodes ricinus, England, Scotland & Wales
(@July, 2024)

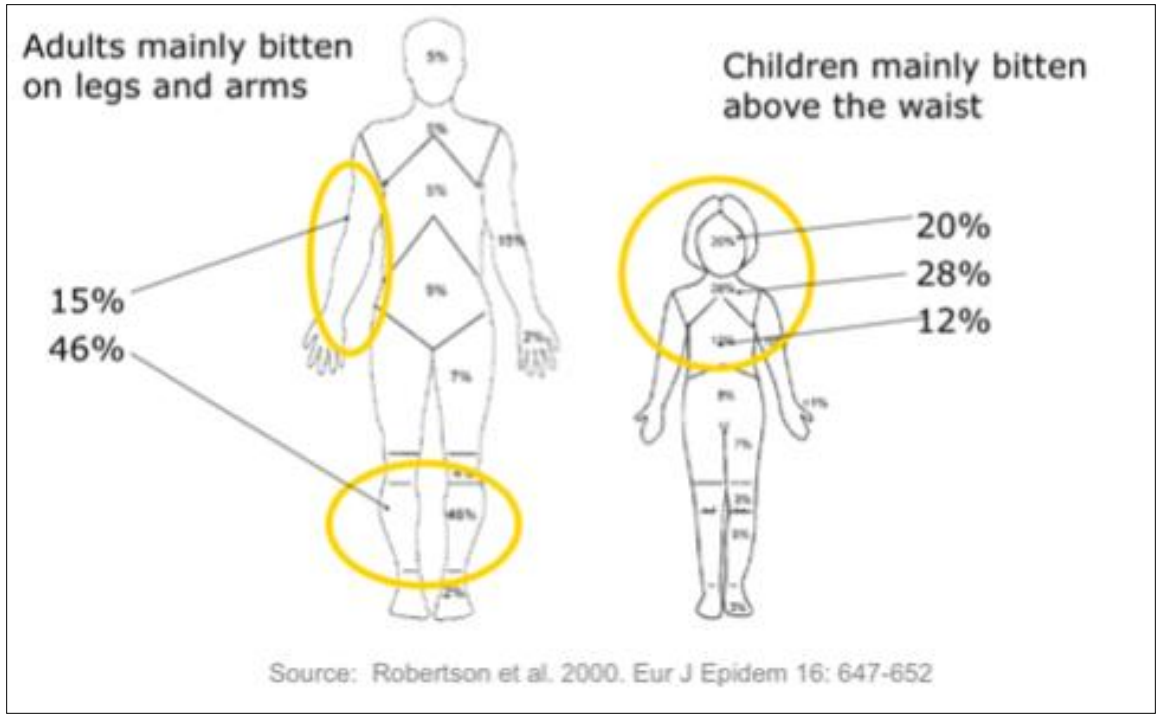


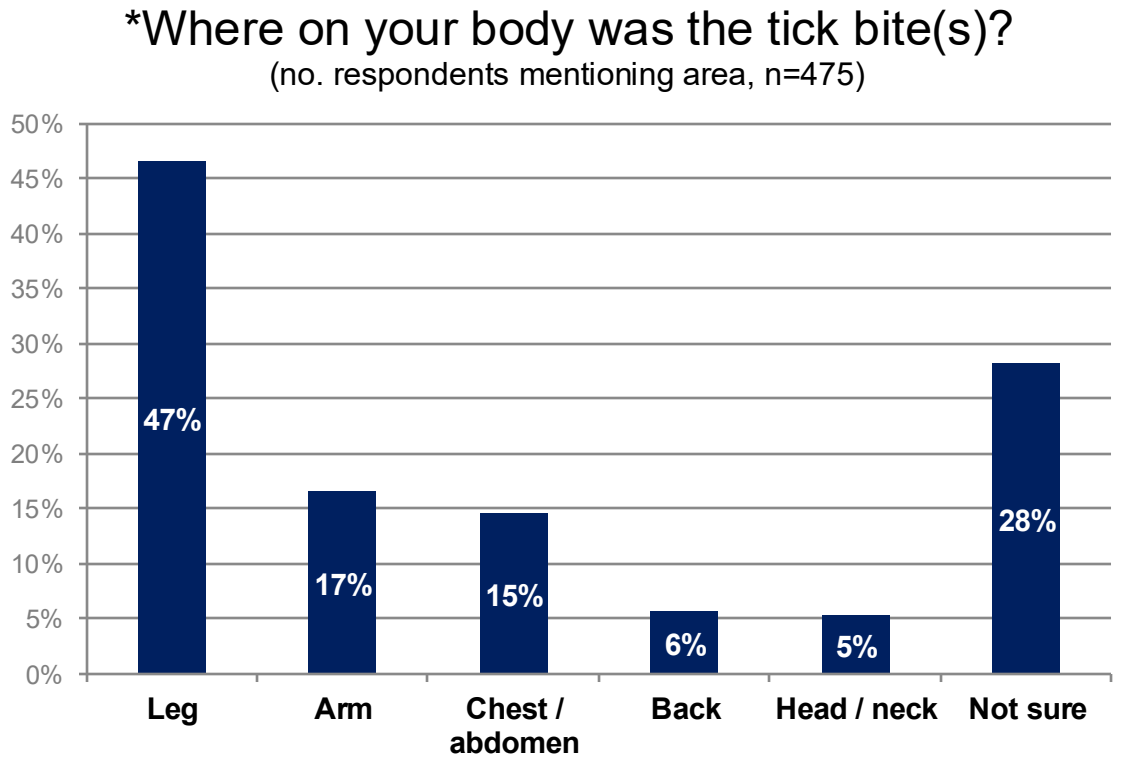
Tick bites

- Tick bites are painless, may go unnoticed
- Nymphs ticks are tiny, size of a poppy seed so easily missed; remain small even when engorged
- Ticks are attracted to, crawl to moist protected areas
- Feeding can continue for days if undisturbed
- The longer the attachment, the greater risk of infection
- No proven minimum time needed for transmission of infection
- Traumatic removal of tick increases risk of transmission of infection
- Not all ticks carry Borrelia - 0-20% (Average 4.5-5%)
- Ticks carry & transmit other pathogens (e.g., Anaplasma, Babesia, Rickettsiae, Tick Borne Encephalitis)



Tick bites

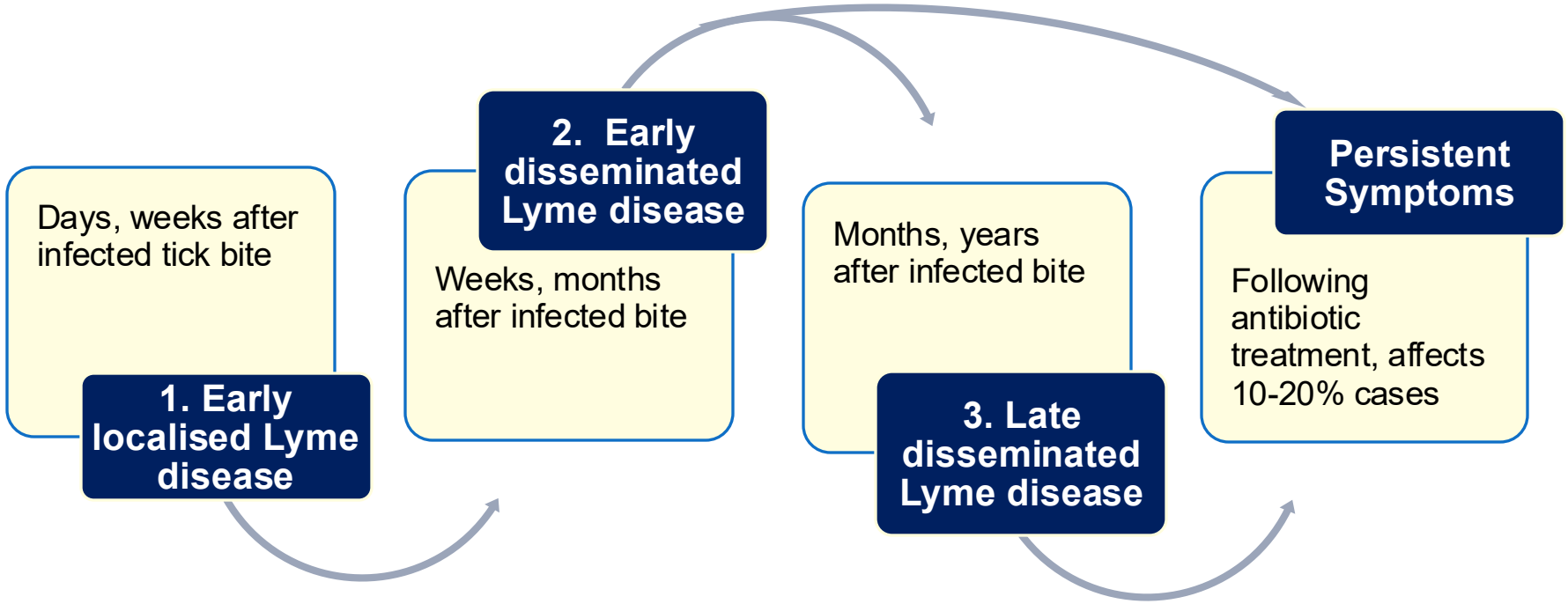




Remember - there may be more that one tick bite!

*Lyme Resource Centre's Lyme Disease Experience Survey, 2024 (n=475)

Defining Lyme disease



- '*Post treatment Lyme disease syndrome (PTLDS)*'
- '*Post treatment Lyme disease* (PTLD)'
- '*Chronic Lyme disease*'
- *'Long Haul Lyme'*

Symptoms of early Lyme disease
(with or without a history of tick exposure)

Erythema migrans (EM) rash **is Diagnostic of Lyme disease (**take a photograph**)**

Also

- Flu-like symptoms
- Fever
- Fatigue
- Headache
- Neck ache
- Myalgia
- Arthralgia

Common barriers to diagnosis

- No history of tick bite
- Absent or atypical EM rash
- Systemic symptoms attributed to viral infection
- Lack of awareness, knowledge of Lyme disease amongst public & health professionals

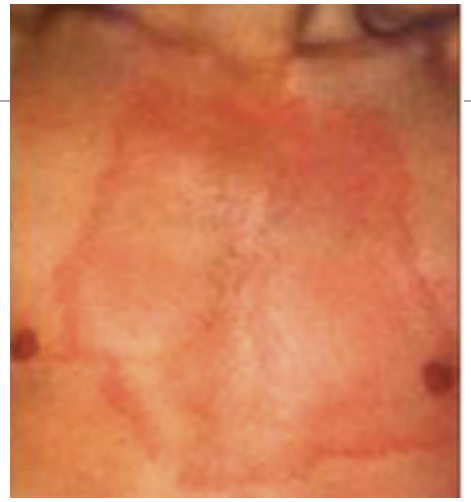
Erythema migrans (EM)

Absent in 30% of cases

Features	Easily misdiagnosed	History is key	Treat
• Usually occurs 3-30 days after tick bite • Expanding red rash – not necessarily a bull's eye • May be atypical – multiple sites, confluent colour, irregular shape • Usually painless, not hot or itchy	• Tick bites may go unnoticed • Easily misdiagnosed - insect bite, ringworm, cellulitis, allergic reaction • May present to GP, pharmacist, practice nurse, emergency department	• Don't be misled by patient assumptions • Outdoor activities – any • Travel – home and abroad • Systemic symptoms	• Spontaneous resolution of rash does not mean infection has resolved • **Treat with antibiotics as per NICE guideline 95 (NG95)**

Erythema migrans Images from NICE Guideline (NG95)

Erythema migrans



- May be irregular in outline, not necessarily at the site of the tick bite
- **Multiple EM rashes indicates disseminated Lyme disease**
- May be heat sensitive (e.g. appear in shower)

Patient history and rash behaviour is essential to distinguish from other conditions such as ringworm, allergy or cellulitis


By Corina G.,
Wikimedia Commons

Ringworm?


Photo by Hans
Braxmeier / Pixabay

Allergy?


www.nhs.uk/conditions/cellulitis/

Cellulitis?

Insect bite or EM rash?

An EM rash may be difficult to distinguish from insect bite - a detailed history will aid diagnosis

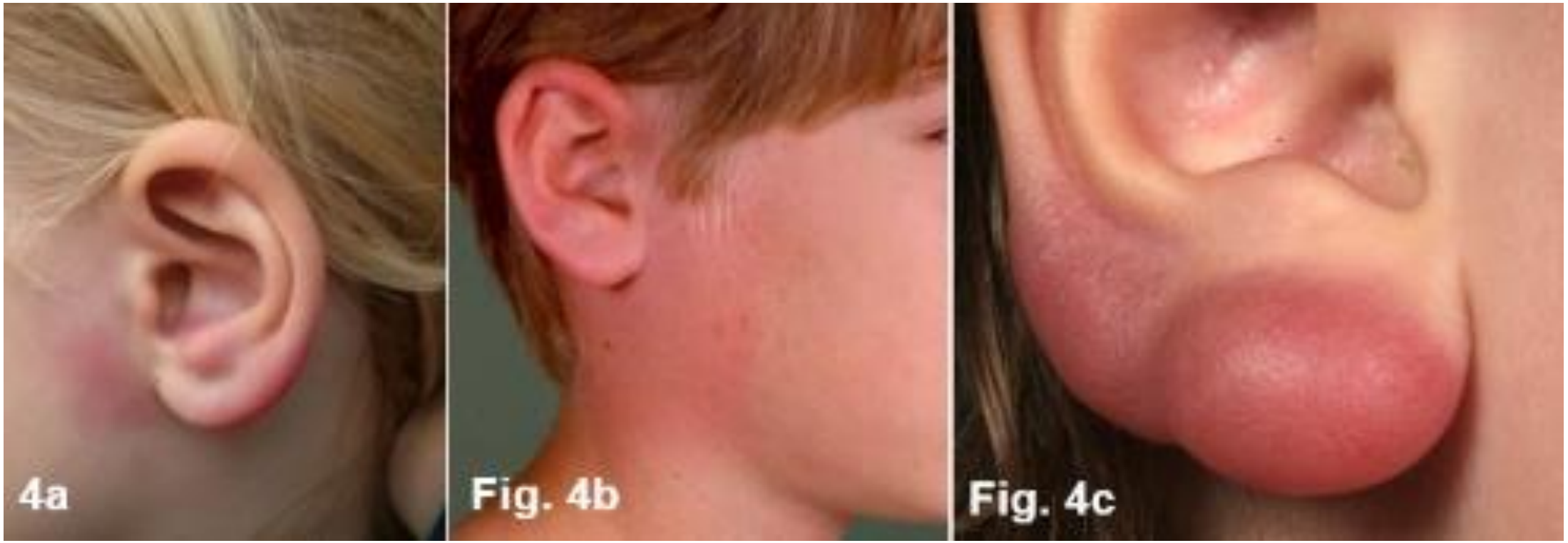
Clinical Features	Allergic Reaction	Infection	Ringworm	Erythema Migrans
Definite recollection of a bite?	Yes / probably	Yes / probably	No	No, unless tick seen and removed
Time to onset	Within hours	Within days	10-14 days from contact	Usually 3-30 days, can be longer
Appearance	Confluent red rash	Confluent red rash; might expand over time	Well demarcated, circular rash; scaly.	Bull's Eye rash or expanding confluent circular, oval red / purple rash; may be multiple
Itchy	Yes	Possibly	Sometimes	Possibly
Hot / warm to touch	Possibly	Yes, might be painful, worsen over time	No	Not usually
Systemic symptoms	Localised or systemic allergic symptoms	Fever or non-specifically unwell	No	Completely well or non-specific flu-like or neuro symptoms

Erythema Migrans and other skin manifestations

Erythema Migrans, Acrodermatitis chronica atrophicans

Other skin manifestations – Borrelial lymphocytoma

‘*Dense infiltration of lymphocytes’* - ears, lips, nipples, scrotum



Hofmann H, Fingerle V, Hunfeld KP, et al. Cutaneous Lyme borreliosis: Guideline of the German Dermatology Society. German Medical Science : GMS E-journal. 2017 ;15:Doc14.

Early disseminated Lyme disease

General	Cardiac	Neurological
• EM rash(es) • Flu like symptoms • Fatigue • Myalgia / arthralgia • Headache • Neck pain/stiffness	• Palpitations • Chest pain • Shortness of breath	• Facial palsy • Anxiety • Cognitive dysfunction • Motor / sensory neuropathy • Severe neuralgic pain • Meningitis / encephalitis

- **May occur days or weeks after becoming infected**
- **Tick bite may have been missed or forgotten**
- **Patient may need prompting to ensure a detailed history**

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

Muskuloskeletal

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

Dematological

- 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)

Paediatric Lyme disease

- Flu-like illness
- Fatigue
- Facial Palsy
- Neurological & psychiatric symptoms
- Headaches
- Unexplained fevers
- Behavioural changes
- Deterioration in school performance

Symptoms may be non-specific & difficult to assess
Can be early or late presentation

High frequency of facial nerve palsy due to Lyme disease in a geographically endemic region (Munro et al, 2020)

Conclusion

- in areas endemic with Lyme disease, Lyme disease should be considered as likely cause of facial nerve palsy in children until proven otherwise.

Testing in context

Key Points

- If EM rash, treat as per NICE guideline
- Clinicians can treat based on clinical suspicion
- If no EM rash but possible tick exposure and symptoms of LD, start treatment and consider test
- Early antibiotics may prevent a positive test, as may immunosuppression
- Better to treat than delay

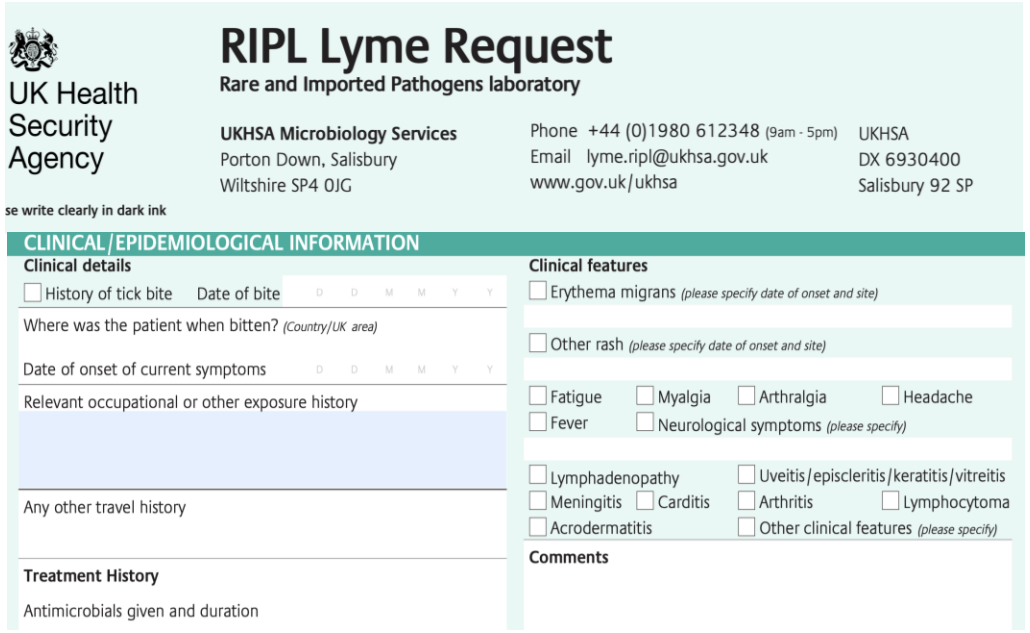
Laboratory diagnostics

Key Points

- Two-tier immune-based test (risk of false negative results)
  - Elisa (IgM/IgG) done at local lab or RIPL, takes 24 hrs
  - Immunoblot (IgM & IgG) RIPL takes 10-14 days
- Request test if Lyme disease suspected (without EM rash)

- Test name ‘Borrelia’ - provide clinical details to aid analysis
- Lyme panel for co-infections (e.g. Anaplasma, Rickettsia, Coxiella)

- Send to local laboratory who will use
  - Rare & Imported Pathogens Laboratory (RIPL), UK (except Scotland)
  - Raigmore Hospital, Inverness



UK Health Security Agency

RIPL Lyme Request

Rare and Imported Pathogens laboratory

UKHSA Microbiology Services
Porton Down, Salisbury
Wiltshire SP4 0JG

Phone +44 (0)1980 612348 (9am - 5pm)
Email lyme.ripl@ukhsa.gov.uk
www.gov.uk/ukhsa

UKHSA
DX 6930400
Salisbury 92 SP

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CLINICAL/EPIDEMIOLOGICAL INFORMATION

Clinical details

☐ History of tick bite Date of bite D D M M Y Y

Where was the patient when bitten? *(Country/UK area)*

Date of onset of current symptoms D D M M Y Y

Relevant occupational or other exposure history

Any other travel history

Treatment History

Antimicrobials given and duration

Clinical features

☐ Erythema migrans *(please specify date of onset and site)*

☐ Other rash *(please specify date of onset and site)*

☐ Fatigue ☐ Myalgia ☐ Arthralgia ☐ Headache
☐ Fever ☐ Neurological symptoms *(please specify)*

☐ Lymphadenopathy ☐ Uveitis/episcleritis/keratitis/vitreitis
☐ Meningitis ☐ Carditis ☐ Arthritis ☐ Lymphocytoma
☐ Acrodermatitis ☐ Other clinical features *(please specify)*

Comments

NICE Guideline (NG95)

Diagnosis – key points

- **Diagnose and treat LD without testing in people with EM rash**
- Use combined clinical presentation & testing to guide diagnosis without EM
- **Do not rule out LD if tests negative but high clinical suspicion of LD**
- Diagnose LD in people with symptoms of Lyme disease and a positive immunoblot

- If negative test and or ongoing symptoms, see NICE guideline for further testing guidance
  - If LD suspected with a negative test within 4 weeks of symptoms onset - repeat after 4-6 weeks
  - If LD suspected with symptoms for more than12 weeks but negative ELISA perform an immunoblot

- **For children and young people less than 18yrs old, discuss with a specialist if more than a single EM rash**

NICE Guideline (NG95)

Treatment – key points

- **Prompt antibiotic treatment reduces the risk of further symptoms developing and increases the chance of complete recovery**
- Dosages are higher and of longer duration than other conditions
- **If clinical suspicion of LD without EM, consider starting treatment while waiting for results**
- **If symptoms persist after first course - give 3 weeks of a different antibiotic**

- No indication for prophylactic treatment following a tick bite
- Treat pregnant women with appropriate antibiotics

- If ongoing symptoms, consider - treatment failure, reinfection, organ damage, review diagnosis, secondary care referral

NICE Guideline (NG95)

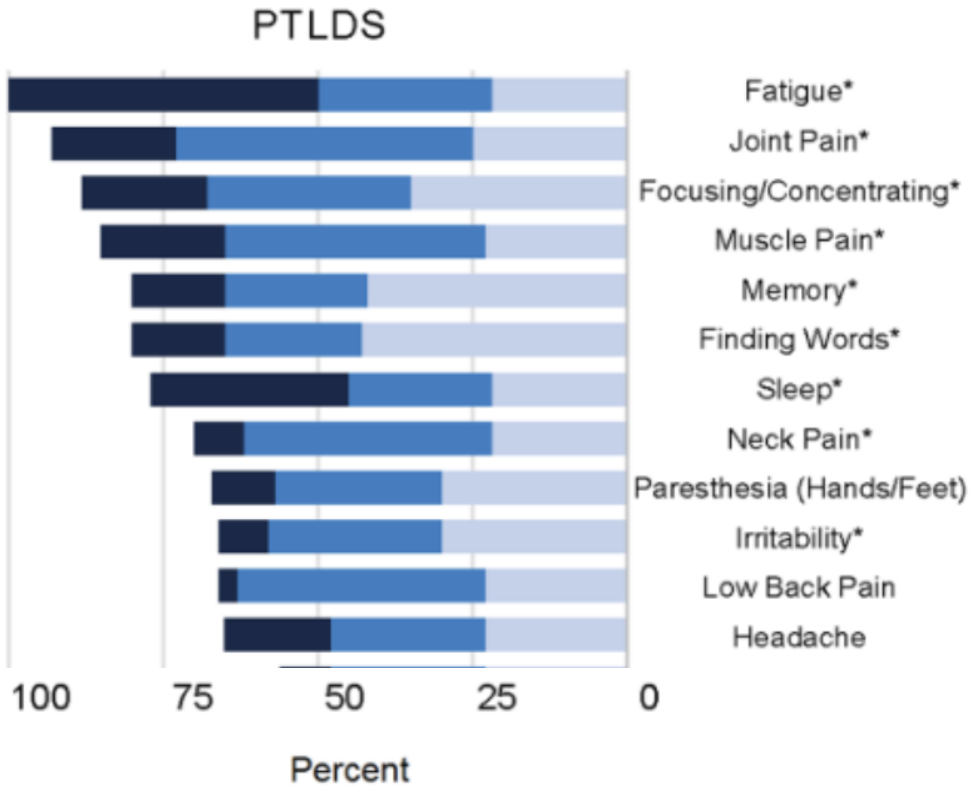
Treatment

Adults	Children
Doxycycline 100mg BD for 21 days ***or*** Amoxicillin 1g TDS for 21 days (e.g. in pregnancy) or Azithromycin 500mg OD for 17 days CNS, cardiac symptoms may require IV ceftriaxone	1st line in children aged 9 - 12 years Doxycycline for 21 days (check dosages) Under 9 years Amoxicillin 30mg/kg TDS for 21 days (under 33kg) Azithromycin 10mg/kg OD for 17 days (under 50kg) *Note: doxycycline & azithromycin off licence but recommended in national and international guidelines*

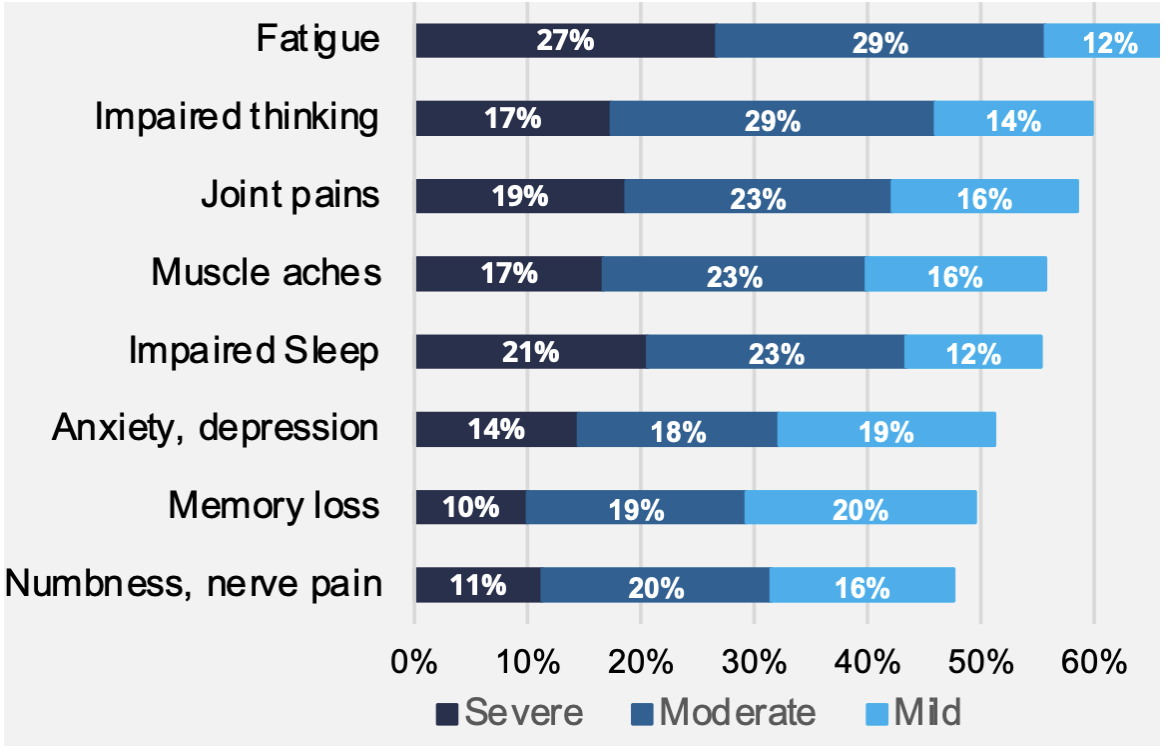
- **Early adequate treatment gives the best chance of cure**
- **Note high dosages, longer durations**
- Warn about Jarisch-Herxheimer reaction
- A second course of a different antibiotic is indicated if symptoms persist

Persistent symptoms

10-20% of Lyme patients continue to have persistent or recurrent symptoms after 2-4 weeks of antibiotic treatment



Johns Hopkins Lyme Disease Research Centre
'Symptoms of PTLDS'



LRC Lyme disease Experience Survey 2024
Most commonly reported ongoing symptoms after treatment for Lyme disease

The ‘New Great Imitator’

Lyme disease, at any stage, be mistaken for many other conditions

Neurological (Neuroborreliosis)

- Bell’s palsy
- Multiple Sclerosis
- Motor Neurone Disease
- Parkinson’s Disease
- Guillain-barré Syndrome
- Chronic pain
- Dementia
- FND

Cardiovascular

- Arrhythmias
- Pericarditis
- Myocarditis

Muskuloskeletal

- Arthritis
- Fibromyalgia
- Ehlers Danlos Syndrome
- Polymyalgia rheumatica

Dermatological

- Insect bites
- Unexplained rashes

Psychiatric / Psychological

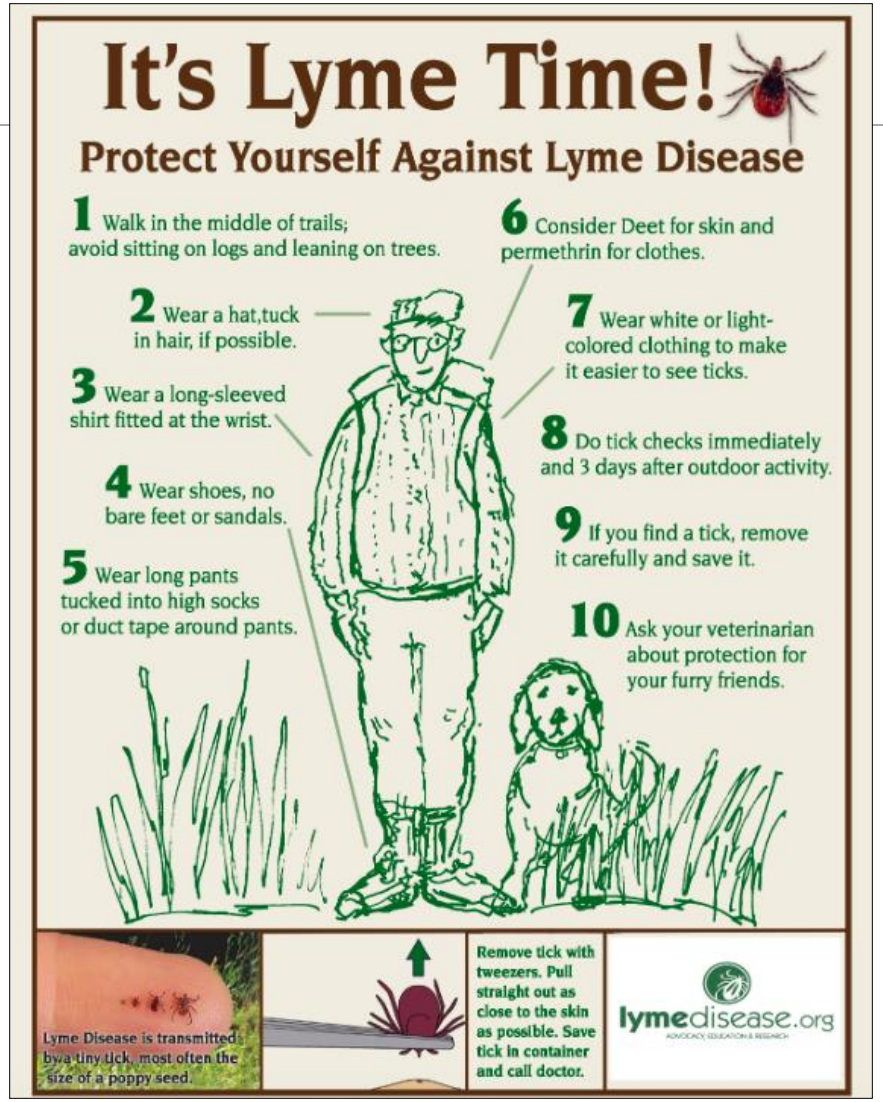
- Anxiety
- Depression
- Psychosis

General

- ME / CFS
- IBS
- B12 Deficiency
- SLE
- Medically Unexplained symptoms
- Long COVID

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 repellant
- 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)

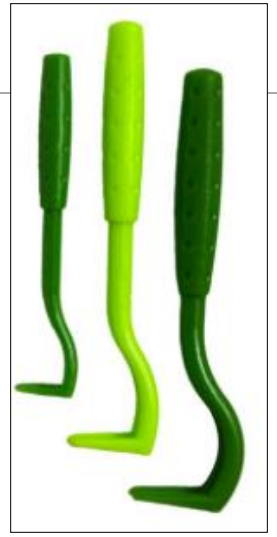
- **62%** not aware of need to protect against tick bites prior to illness
- **69%** not aware of signs and symptoms of Lyme disease prior to illness
- **33%** did not remember a tick bite

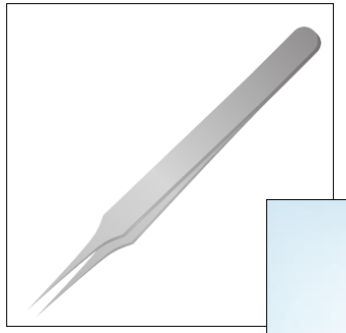
*Lyme Resource Centre's Lyme Disease Experience Survey, 2024 (n=475)

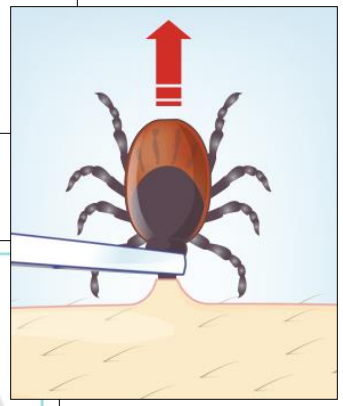
Removing a tick

✓ 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 ✗

- 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

After a tick bite.....

If asymptomatic

Record details
- Date, location of tick exposure or bite
- Site of bite and length of attachment

Check for symptoms
- Any rashes or flu-like symptoms

Risk advice
- Explain possible Lyme disease risk
- Recommend returning if symptoms develop

Consider tests, treatment
- Determine if testing is needed.
- Prophylactic treatment not indicated

If symptomatic

- If EM rash + / - clinical signs suggest Lyme disease

- Initiate treatment

Further actions

Tick bite prevention
- Advice on tick bite avoidance
- Education of at risk groups (e.g. parents, children, workers spending time outdoors)

Signpost to resources
- NICE Guideline 95
- Lyme disease charities
- UKHSA

CASE STUDY

Late Presentation of Lyme Disease in a 55-Year-Old Female: Diagnostic & Therapeutic Challenges'

Context

This case illustrates multiple missed opportunities for early diagnosis and treatment of Lyme disease in a primary care setting. It highlights the long-term impact of delayed recognition and serves as a reminder of the importance of thorough history-taking, especially regarding outdoor exposure.

Patient Presentation

- **Patient:** At that time the patient was 43-year-old female nurse, previously well
- **Initial Symptoms**
  - Following a picnic with her young children in high summer at Cotswold Water Park, developed flu-like symptoms the next day
    - Myalgia, shivering, headache
    - Swelling of fingers and toes (unable to remove wedding ring)
- **Initial GP Visit**
  - Viral illness suspected- minimal history taken.
  - Advised paracetamol and to return if symptoms worsened
  - Symptoms resolved within days

Case Study: Late presentation of Lyme disease in 55 year old female

2004 - 2008

- Recurrent evening shivers, fatigue, malaise, bilateral knee effusions a few months after initial consultation.
- Multiple GP visits over the four years.
- Bloods: Slightly low Hb, raised CRP, low platelets
- Diagnosis: “Likely post-viral syndrome”

2010 - 2012

- Symptoms escalated - myalgia, cold sensitivity, fatigue. Bilateral knee effusions.
- Referred to consultant in General Medicine; ? Post viral syndrome of some sort.
- Further referrals to Birmingham hospital to see an immunologist as “ so puzzling”.

2015

- Became acutely unwell
  - Shivering, joint effusions (knees), palpitations, rib and back pain
  - Swelling and tenderness in hands/feet
- Investigations
  - Raised CRP, plasma viscosity, weakly positive rheumatoid factor
  - ?Autoimmunity / early RA considered
  - Prescribed HRT (suggested menopause as trigger)
- Referred to rheumatology: RA excluded; diagnosed with enthesitis

Case Study: late presentation of Lyme disease in 55 year old female

Turning Point

- Patient, now trained in diagnostic reasoning and extended prescribing. Vaguely recalled past lecture referencing **Lyme disease**.
- Requested Lyme testing from GP
- **Result Positive** (confirmed via RIPL, Porton Down)
- Treated with doxycycline (2 weeks + 4 weeks) — **partial improvement**
- Referred to specialist clinic → combination of doxycycline & azithromycin (3 months)

Further Management

- Imaging - bilateral knee effusions noted
- Sought further treatment at private Lyme clinic in Germany. Rifampicin added in .
- **Ongoing**: periodic flares managed with lifestyle strategies and complementary therapy

Key Issues Raised

- Numerous GP visits, 4+ consultant appointments, bloods, imaging
- **Missed Opportunities:**
  - No tick exposure history taken until years later
  - Delay in diagnosis despite clear symptom clusters
  - Lack of awareness in Lyme presentations
- **Patient-led diagnosis -** self-advocacy played a key role in identifying the cause

CASE STUDY

Case Study: Late presentation of Lyme disease in 55 year old female

Learning Points for Primary Care

- Be alert to **variable presentations** of Lyme (flu-like symptoms, joint issues, fatigue)
- Take a thorough **exposure history** — recent travel, outdoor activity, tick habitats
- Understand the **limitations of Lyme testing** and when to refer
- Recognize the **psychosocial burden** of prolonged undiagnosed illness

Takeaways for Clinicians

1. Always ask about **outdoor exposure**, even with vague symptoms
2. Don’t overlook Lyme in patients with **persistent, unexplained systemic symptoms**
3. Early suspicion and treatment can prevent **long-term morbidity**
4. **Ask about EM rash**

Practice Pearl: ***If you don’t ask about ticks, you won’t find Lyme***

Spread the Word!

- Champion for your area - lead role
- Update colleagues or team on study day
- Clarify roles e.g. pharmacy first – collaborate with pharmacies.
- Involve, awareness with receptionists and all members of PHCT
- Put on agenda for team updates / meetings
- Consider Lyme disease for those puzzling patients and have a greater sense of suspicion
- Clarify whose role to request blood test
- Campaigns in peak tick activity - e.g. text practice population
- Make sure you keep tick removers!
- Scope of practice for nurses

Learn more

Key Takeaways

- Lyme disease is a complex multi-systemic disease which can be difficult to diagnose
- Early and adequate treatment provides the best chance of full recovery
- Erythema migrans - diagnostic of Lyme disease
- Serological testing may be unreliable
- Unusual multi-systemic, fluctuating symptoms - consider Lyme disease & explore history
- If patient / parent suspects Lyme disease - take them seriously

http://www.rcgp.org.uk/clinical-and-research/resources/toolkits/lyme-disease-toolkit.aspx

http://elearning.rcgp.org.uk/course/info.php?popup=0&id=164

http://nice.org.uk/guidance/ng95

www.lymeresourcecentre.com

https://lymediseaseuk.com/

LRC

LYME RESOURCE CENTRE

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.

Outdoor awareness signage

Resources for schools & youth organisations

Awareness posters & leaflets

LRC resources are freely available – visit www.lymeresourcecentre.com or contact admin@lymeresourcecentre.com

Questions?