Live Well
Wellness Essentials

Understanding Lyme Disease

Deborah Bircham

Health Coach, Mindfulness Teacher

Holistic and Naturopathic Wellness

QUALIFICATIONS:

- ✓ Naturopathic Nutrition and Health Coaching: *Diploma-College of Naturopathic Medicine (CNM)*
- ✓ Hypnotherapy and Psychotherapy: *Mindworks*
- ✓ Mindfulness Teacher: *Teach 10 Institute*

MEMBERSHIPS:

- ✓ National Council for Integrative Psychotherapists (NCIP)
- ✓ UK & International Health Coaching Association(UKIHCA)
- ✓ The Association of Naturopathic Practitioners (ANP)
- ✓ The Personalised Care Institute

Lived Experience of Lyme Disease, MCAS, Dysautonomia and Chronic Pain

Socials: Live Well With Chronic Illness
Email: livewellwithchronicillness@outlook.com
Website: https://livewellwithchronicillness.co.uk

Understanding Lyme Disease

Cases of Lyme Disease are on the rise worldwide, and now endemic in ticks across the UK

Around 3,000 cases recorded each year in the UK, but the actual figures are thought to be very much higher.
In the US, more than 476,000 people are infected (conservative)
By 2050, projected figures are that around 17% of European population will be infected with Lyme. (134.9 million people) https://pmc.ncbi.nlm.nih.gov/articles/PMC5872223/

The most common tick-borne disease in the Northern Hemisphere

It can affect adults and children of any age

A lot of confusion, controversy, lack of information and misinformation

Considered by many to be an emerging global health crisis, that can have profound and long-term implications for millions of people. Dr Tania Dempsey calls it 'A silent pandemic.'

Really important for everyone to become aware of Lyme Disease and how to protect yourself and your loved – ones.

Disclaimer

Lyme is controversial and complex, and there is a lack of understanding about it

What I'm going to share is based on the latest published research, the RCGP Lyme Disease Toolkit, and available resources from Lyme Disease UK and other reputable Lyme-Disease authorities.

There are references and research papers to back up everything I am going to share

None of it is 'made up' or based solely on my own opinion.

According to the RCGP Toolkit 'There is ongoing medical and scientific uncertainty and conflicting opinion in relation to many aspects of diagnosis and treatment of Lyme disease. There is a recognised need for further research in order to address core uncertainties and improve patient outcomes.'

Disclaimer

Not intending to cause anxiety or alarm!

Information to allow you to make informed decisions

About how to care for yourself and your family

Awareness of information allows you to be safer

Forewarned is forearmed!

MCAS and Lyme Disease

There is evidence that Lyme and other bacterial infections can trigger MCAS

Some leading US Lyme doctors recognize MCAS as a factor in around 50% of their Lyme patients

We will look at the evidence for the connection later in this talk.

If you can't identify an external trigger for your MCAS, or you can't get it under control despite removing external triggers, consider if there might be an internal trigger.

My Story

2017 – 2018 I was working in woodlands all over the country delivering events and engagement

Early 2018 I noticed a huge bite on my leg

Feb 2018 I missed my friend's 50th Birthday party due to 'flu'

March 2018 I became catastrophically ill, with a whole myriad of mysterious symptoms.

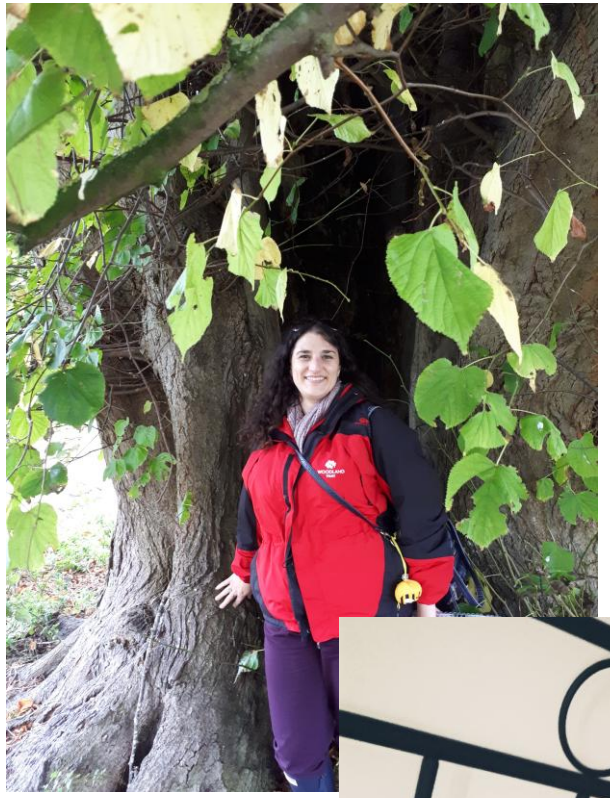
Complete insomnia, tachycardia, excruciating chest pain, heart inflammation, brain fog, memory loss, dizziness, twitching, muscle spasms, numbness, seizures, swollen lymph nodes, bruises and rashes, visual disturbance, tinnitus.

I lost my job, I couldn't drive, I was housebound, some days bedbound

I couldn't do a jigsaw for an 8-year old

It took 2 years to be diagnosed with Lyme Disease, and another year to get on the right treatment, by which time it had become systemic and had triggered MCAS.

For me, treating Lyme has significantly improved my MCAS



What is Lyme Disease?

Lyme Disease is a bacterial infection

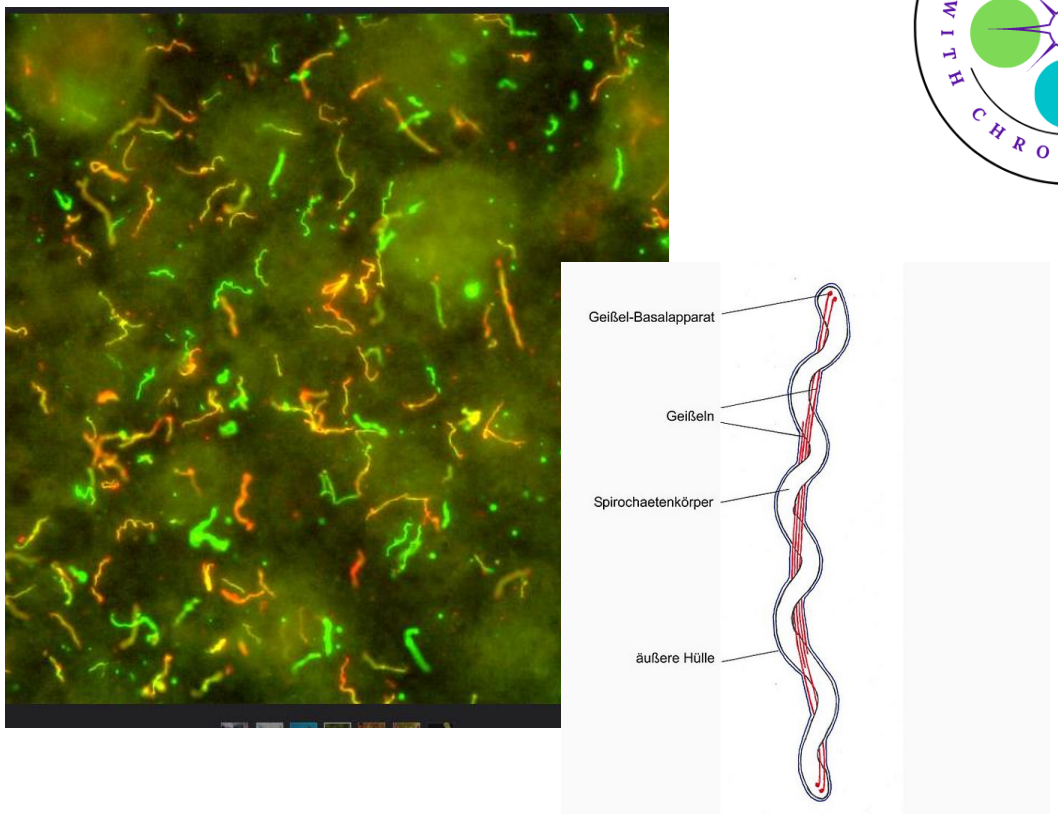
Borrelia Burgdorferi Bacteria

The bacteria are ‘spiral’ in shape

Known as ‘spirochetes’

Same type of bacteria as syphilis

Corkscrew form means they can burrow deep into tissues



Can also mutate into ‘round body’ forms which are resistant to antibiotics (British Journal of General Practice)

2016 study found that antibiotics left over 68% of round body Lyme cells alive, and also induced spirochetes to ‘morph’ into round body forms

Credit: NIAID https://www.flickr.com/photos/niaid/5661846104/in/photostream/
Brudersohn - Own work (Original text: *selbst gezeichnet*)
https://projectlyme.org/lyme-persists/antibiotic-resistant-round-bodies/

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4876775/
https://bjgp.org/content/lyme-disease-bacteria-can-form-structures-confer-resistance-antibiotics-and-protection

How Do You Catch Lyme?

- Being bitten by an infected tick
- Ticks are a member of the arachnid family – they have 8 legs
- They can be found in any area where there are wild birds or animals – Questing Behaviour
- Deer, squirrels, birds, rats, and other animals all carry ticks
- There is no minimum time for a tick to be attached for transmission
- There is some emerging evidence that Lyme may also be transmitted by other biting insects. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC266646/
- **Not all ticks carry the bacteria that causes Lyme (UK 4-10%)**

Ticks can be found

- Long grass
- Leaf litter
- Rocks
- Fallen logs
- Tree trunks

Image by Erik Karits from Pixabay

Ticks

There are 3 stages in the life cycle of a tick

Larva
Nymph
Adult

Due to climate change, ticks are now present throughout the UK
Most active April – July, also autumn. However, they are present all year round - people have been infected on Christmas Day.

The nymph ticks are most likely to bite humans, and most cases of Lyme Disease are transmitted by nymph ticks.

Many people are bitten by nymph ticks and do not know it.

In the UK the main vector for Lyme is
Ixodes Ricinus (Castor Bean Tick or Sheep Tick or Deer Tick)
Hard bodied tick

Getty Images Istock photo RobertAx

Facts about Tick Bites

You can be bitten by a tick and not realise it – many people with Lyme Disease do not remember a tick bite. According to RCGP only 1 in 3 notice a bite.

You can be bitten by a tick in any location – in your garden, in parks, in urban areas – not just woodlands and fields.

You can be bitten by a tick on **any** part of your body

Tick bites are usually painless and **generally** do not itch, so they often go unnoticed. (There may be a histamine response)

Adults tend to be bitten on the lower body – groin, legs, behind knees
Children tend to be bitten on the upper body, behind ears, in hairline

History of Lyme Disease

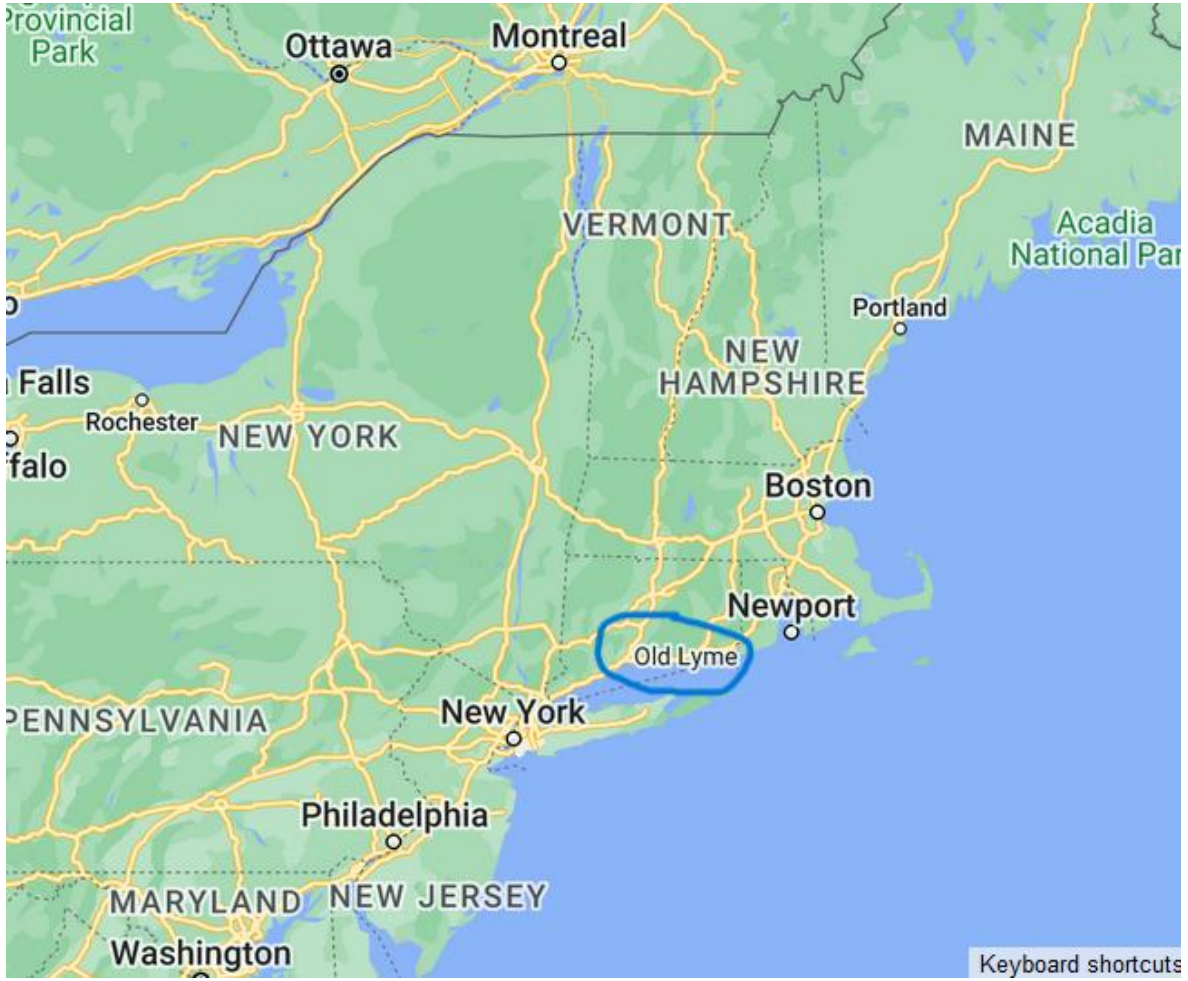
It is ‘Lyme’ Disease, not ‘Lymes’

It is named after the town of Old Lyme, in Connecticut, USA.

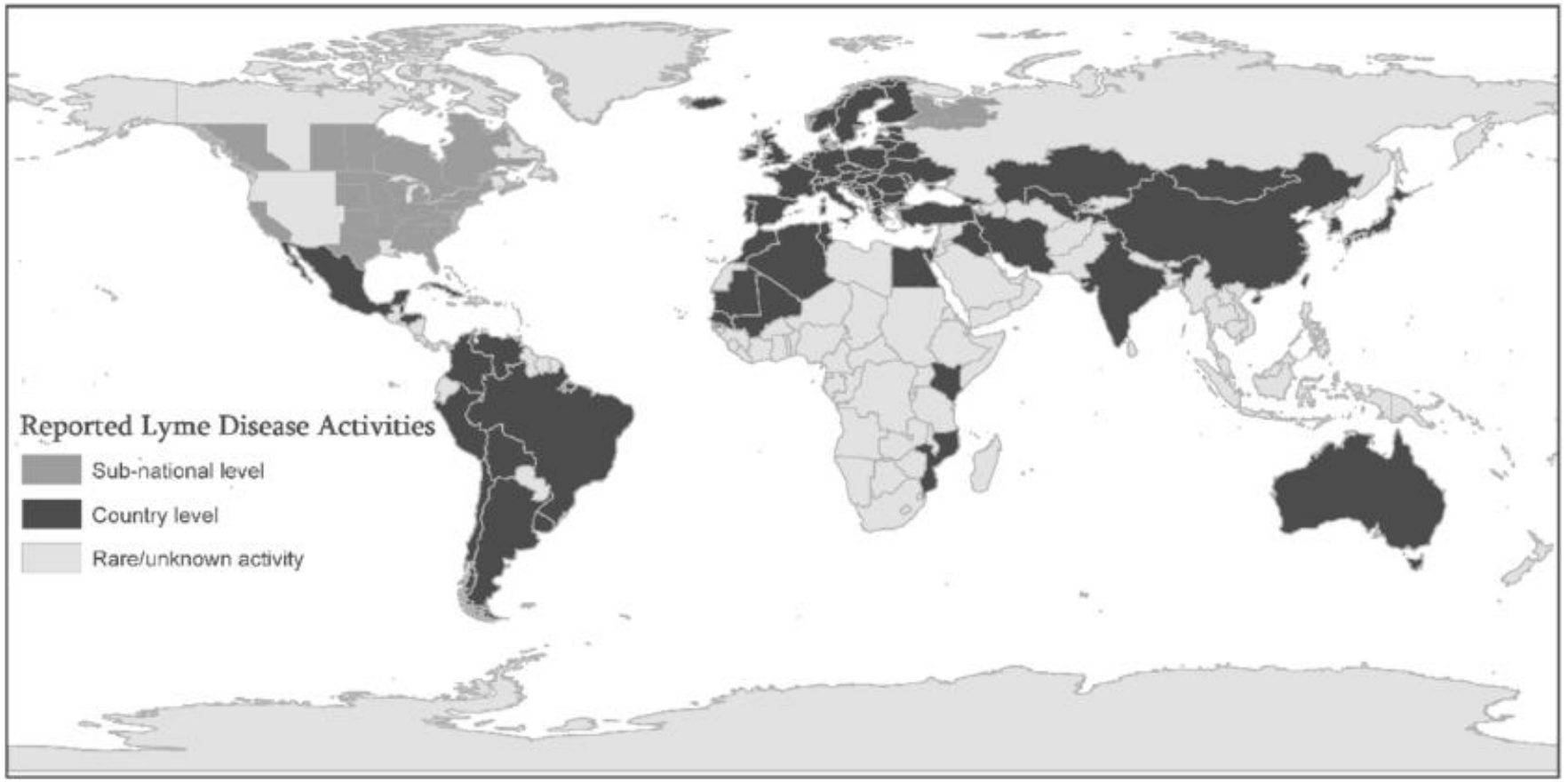
In the 1970s, lots of children developed mysterious symptoms similar to arthritis, this was the first modern recognised incidence of Lyme Disease.

In 1982, scientist Willy Burgdorfer identified the bacteria that causes Lyme Disease, and Borrelia Burgdorferi is named after him.

A variant of Borrelia burgdorferi DNA has since been identified in the 5,000 year old ice-age mummy, Ötzi, Found in the Austrian/Italian Alps.



Where are Lyme Disease-Carrying Ticks Found?



Central and Eastern Europe and Northeastern States of the USA

Antarctica!

"GIS and Remote Sensing Use in the Exploration of Lyme Disease Epidemiology". Esra Ozdenerol https://www.researchgate.net/figure/Geographic-Extension-of-Lyme-Disease-LD-activities-Figure-1-shows-that-Lyme-Disease_fig1_285547037

Precautions to Prevent Tick Bites

- Tick repellents – sprays and essential oils
- Cover skin – tuck trousers into socks
- Avoid long grass and overgrown areas
- Avoid brushing against vegetation
- Wear light coloured clothing so that ticks are more easily noticed
- Carry out tick checks - especially on children and domestic animals
- Pet owners are one and a half times more likely to be bitten by a tick than non-pet owners. (Animals may carry ticks into the home. RCGP Toolkit)
- Change clothing promptly when returning home from time spent outside – do not leave clothing lying around on beds etc

Image by Pexels from Pixabay

What to Do If You Are Bitten By A Tick

Prompt correct tick removal is the primary key to prevention of Lyme disease.

It is essential to remove a tick correctly with a Tick Remover Tool or sharp-nosed tweezers

Do NOT squeeze a tick

Do not use blunt tweezers

Do not burn or stress a tick

Do not cover with Vaseline or other substance

A stressed tick will be more likely to vomit and regurgitate its stomach contents – increasing the likelihood of catching Lyme.

How to safely remove a tick with a tick tool

https://www.youtube.com/watch?v=j36Cw7utM7E

Can save and test tick

https://biobest.co.uk/

Lyme Disease Transmission

Congenital infection. Lyme Disease can cross the placenta and infect an unborn child.

Research first proved that congenital transmission was possible in 1985, but the CDC in the USA did not update their guidelines to reflect this until 2020.

Sexual transmission. It is possible that Lyme disease can be sexually transmitted, although more research is needed. 2014 study found live Lyme spirochetes in semen and vaginal secretions of people with documented Lyme.

Blood transfusion. A 1990 study showed Borrelia bacteria survived in blood that had been processed for transfusion. The NHS does not screen blood donations for Lyme Disease.

Image by Iuliia Bondarenko from Pixabay

https://pubmed.ncbi.nlm.nih.gov/2685924/
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5482345/
https://pubmed.ncbi.nlm.nih.gov/2373880/
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6231644/
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9669415/

Ticks – Nature's Dirty Needles

Not Just Borrelia! Around 50% of people with Lyme also have co-infections

- Bartonella
- Mycoplasma
- Ehrlichia
- Anaplasma
- Yersinia
- Babesia
- Tick-borne encephalitis (1st UK case 2019)

Size of this preview: 800 × 545 pixels. Other resolutions: 320 × 218 pixels | 640 × 436 pixels | 1,024 × 698 pixels | 1,280 × 873 pixels | 2,200 × 1,500 pixels.

https://en.wikipedia.org/wiki/File:Ixodus_ricinus_5x.jpg Richard Bartz

For many people, it is the co-infections that are the main drivers of symptoms

Bartonella is particularly difficult to eradicate, and causes extremely unpleasant neurological and mental/emotional symptoms.

Many people with treatment-resistant symptoms may not be receiving the correct treatment for their co-infections.

Identifying and treating co-infections is key to recovery.

https://www.researchgate.net/publication/299531772_Impact_of_Co-Infections_in_Lyme_Disease

https://www.mdpi.com/2076-0817/12/11/1371

https://openneurologyjournal.com/VOLUME/6/PAGE/158/FULLTEXT/

What are the Symptoms of Acute Lyme Disease? RCGP Toolkit

‘The Borrelia bacterial disseminate quickly around the body, causing wide-spread, multisystemic symptoms.

Initial symptoms after a tick bite may include
flu-like symptoms
Possible EM rash
fever and sweats, swollen lymph nodes, malaise, fatigue, neck pain, migratory myalgia or arthralgia, brain fog, headaches, paraesthesia.

Symptoms of Lyme may nervous system, joints, skin, heart and eyes. Lyme disease is known to adversely affect the immune system which may result in a relapsing-remitting clinical picture, often characterised by pain and fatigue.

In the UK and Europe, disseminated Lyme disease is more likely to affect the nervous system, ….with the potential to cause a wide range of diverse neurological symptoms.
Lyme arthritis is more typically seen in North America.’

Image by myshoun from Pixabay

What are the Symptoms of Acute Lyme Disease? NICE Guidelines

1.2.4 Consider the possibility of Lyme disease in people presenting with symptoms and signs relating to 1 or more organ systems

•neurological symptoms, such as facial palsy ....meningitis, ...unexplained radiculopathy; or rarely encephalitis, neuropsychiatric presentations...
•inflammatory arthritis affecting 1 or more joints that may be fluctuating and migratory
•cardiac problems, such as heart block or pericarditis
•eye symptoms, such as uveitis or keratitis
•skin rashes such as acrodermatitis chronica atrophicans or lymphocytoma.

1.2.5 If a person presents with symptoms that suggest the possibility of Lyme disease, explore how long the person has had symptoms and their history of possible tick exposure, for example, ask about:
•activities that might have exposed them to ticks
•travel to areas where Lyme disease is known to be highly prevalent.

The Erythema Migrans Rash (Bullseye Rash)

Credit: Getty Images Istock Photo anakopa

Around 30% of cases don't have a rash at all

It usually develops between 3 to 30 days of a tick bite, but may take longer.

The appearance varies - it may appear as an area of uniform redness rather than a 'bull's eye'. Many people experience atypical rashes, multiple rashes.

Appearance is different on dark skin.

Typically painless and not hot or itchy.

Often present at the site of the bite, but can be anywhere – MIGRANS

'There may be multiple, sometimes transient, erythema migrans rashes on other areas of the body.' RCGP Toolkit

'An EM rash may resolve without antibiotic treatment. However this does not indicate that the infection itself has resolved. If left untreated the disease may disseminate around the body.' RCGP Toolkit

Behaviour of the rash is key – will spread outwards
Draw around it and monitor the spread

Can be circular, oval or blotchy, may have a central blister

Can be red, blue, purple, yellowish

https://lymediseaseuk.com/lyme-rash/

The Erythema Migrans Rash (Bullseve Rash)

Image credit Lyme Disease UK

Credit: Getty Images Istock Photo anakopa

What to Do if You Suspect You May Have Acute Lyme after recent tick bite

Image by estableman from Pixabay

Tick bite or exposure to tick environment

EM Rash - possibly

Flu

Widespread symptoms – pain, fatigue, neurological, cardiac

Immediately Contact your GP, 111 or A&E

Seek Medical advice ASAP – Do Not Delay!

Take a copy of the NICE Guidelines and the RCGP Toolkit to aid with diagnosis and treatment

Presence of Bullseye rash is diagnostic in itself, and does NOT require further testing. Antibiotics should be prescribed immediately

NICE GUIDELINES 1.2.11 Diagnose and treat Lyme disease without laboratory testing in people with erythema migrans.

Testing for Lyme Disease

Complex and Controversial and inaccurate

Currently a 2-tier system

Standard NHS test is an antibody test - ELISA (Enzyme-Linked Immunosorbent Assay)

If this is positive or inconclusive - a second, Immunoblot (Western Blot) should be ordered from Porton Down.

NICE 1.2.18 If Lyme disease is still suspected in people with a negative ELISA who have had symptoms for 12 weeks or more, perform an immunoblot test.

This is not often done!

Timing of the testing is crucial

Antibody testing – testing too early – within 4 weeks of bite

Image by Anna from Pixabay

There is NO 100% reliable test for Lyme and a negative test CANNOT rule out Lyme Disease. (NICE Guidelines and RCGP)

Testing for Lyme Disease

Problems with testing.

Sensitivity – catches ALL the people – no false negatives
Specificity – catches ONLY the people – no false positives

Antibody testing - antibody production affected by Lyme

The ELISA tests give a very high percentage of false negatives. (Not sensitive enough)

Alternative testing companies in US and Germany who have adjusted the sensitivity to account for the reduced antibody-production in Lyme – are considered by many to be much more accurate.

The NHS won't recognise because they believe they are not specific enough (too many false positives)

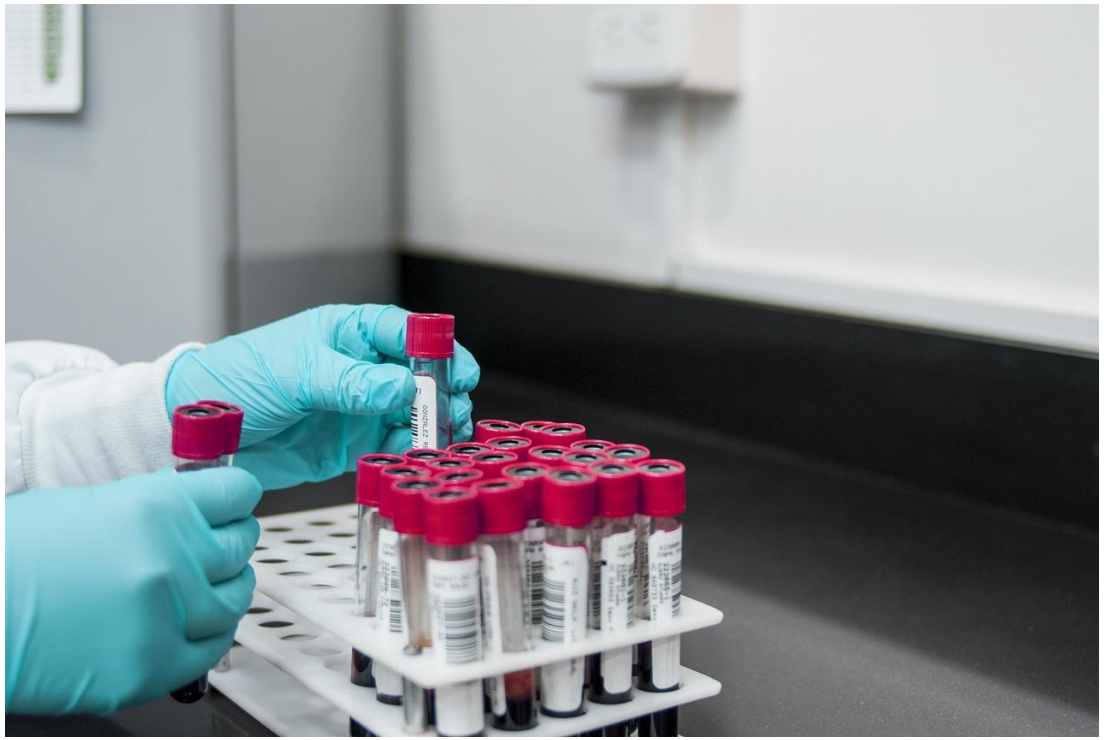


Image by fernando zhiminaicela from Pixabay

There is NO 100% reliable test for Lyme and a negative test CANNOT rule out Lyme Disease. (NICE Guidelines and RCGP)

Lyme Disease and The Immune System

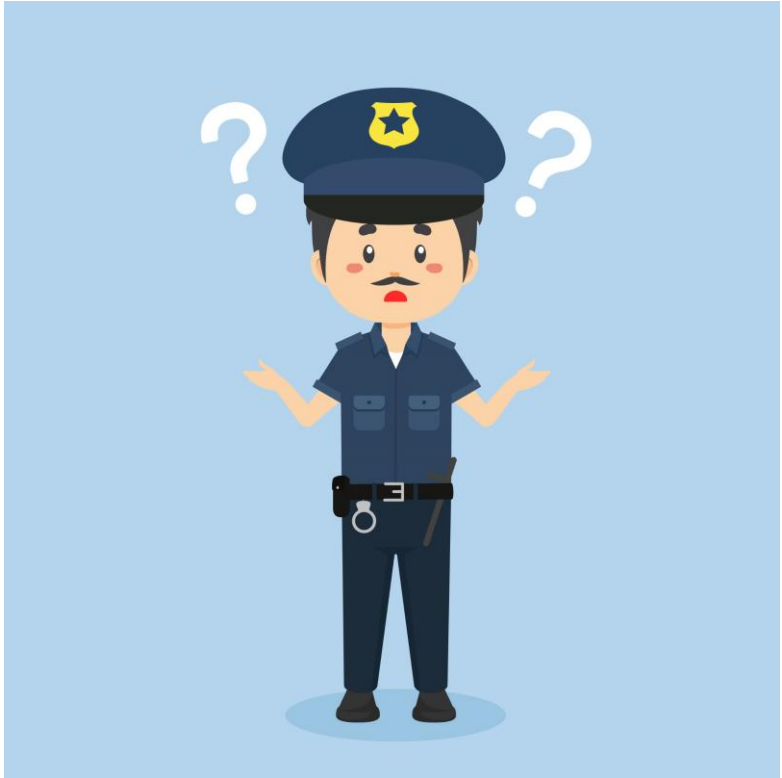
Borrelia eludes the immune system in many ways.

It has the ability to keep changing its outer surface proteins, so presenting the immune system with an ever-changing target.

This confuses the immune cells and they are unable to identify the Borrelia bacteria to attack it, and it can ‘hide in plain sight’.

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3636972/

This paper gives the analogy of the immune cells being like policemen, and meeting together to try and figure out ‘which way the suspects went’!



Vector image by VectorStock / HappyDwiS

This is why antibody tests are not ‘sensitive’ enough

https://www.survivingmold.com/shoemaker-protocol/examining-lyme-spirochetes-bag-of-immune-evasive-tricks

Testing for Lyme Disease

IgM and IgG confusion

IgM is normally the ‘first’ antibody response, created quickly in the early days of infection
IgG antibodies are made later.

In Lyme, IgM antibody production often persists long into the infection, and an IgM positive test does not necessarily indicate a recent infection.

The test instructions for the immunoblot carried out at Porton Down for Lyme acknowledges this.

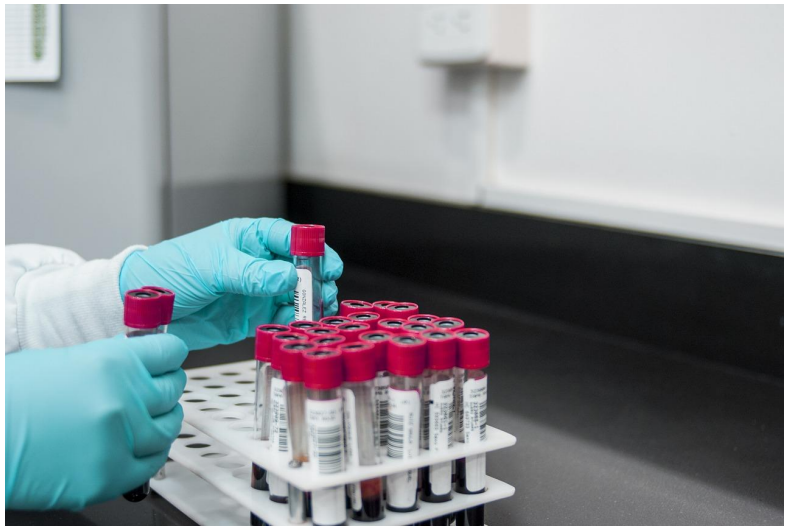


Image by fernando zhiminaicela from Pixabay

page 4, point 2:
“IgM antibodies usually appear 2-3 weeks after onset of the disease for the first time (22). Antibody titers often decline several weeks to months after convalescence. But they may also persist up to several years (7,11,20).” From:
http://www.viramed.de/images/stories/pdf/Arbeitsanleitungen_EN/2551_Borrelia_ViraStripe_IgM_AL_en.pdf
Credit Louise Alban

Testing for Lyme Disease

From the RCGP Toolkit

Diagnosis can be difficult and should be based on a detailed clinical history (including travel history) and examination.

Lyme serology tests may be unreliable, especially in early disease. A negative test does not exclude the diagnosis. There is no test of disease activity or cure.

From NICE GUIDELINES

1.2.12 Use a combination of clinical presentation and laboratory testing to guide diagnosis and treatment in people without erythema migrans. Do not rule out diagnosis if tests are negative but there is high clinical suspicion of Lyme disease.

There is NO 100% reliable test for Lyme and a negative test CANNOT rule out Lyme Disease. (NICE Guidelines and RCGP) Diagnosis should be 'clinical'.

Treatment of Lyme Disease

- NICE Guidelines

Oral doxycycline:
100 mg twice per day or 200 mg once per day for 21 days

Alternative antibiotics

Amoxicillin 1g 3 times a day for 21 days
Azithromycin 500mg daily 17 days

Much longer and stronger dose than most infections

Drs often under prescribe, based on ‘standard’ antibiotic infections.

2018 NICE Guidelines were revised to reflect recent research that shows Lyme Disease is particularly resistant to antibiotics and can be difficult to eradicate.

Check you are being given the correct dose of antibiotics – undertreatment is a leading cause of long-term symptoms

In many cases, prompt diagnosis and treatment with correct antibiotics is enough to ensure full recovery

If symptoms don’t resolve after 1st course of treatment – NICE Guidelines allow for a second course. This is often not offered.

‘Consider a second course of antibiotics for people with ongoing symptoms if treatment may have failed.’ NICE Guidelines

Jarisch-Herxheimer Reaction

‘Herx’
Similar to treatment of Syphilis

When spirochete bacteria die, they release toxins which triggers the immune system

This causes systemic inflammation and worsening of symptoms.

Can include fever, chills, pain, headaches, and severe worsening of any existing symptoms

Can start soon after starting treatment, or after a few days

Can last for a few hours or several days or weeks

Can be brutal

- ‘Be aware of the possibility of a Jarisch-Herxheimer reaction.’ RCGP Toolkit

Statistics Acute Lyme

The Lyme Resource Centre in Scotland has just published the results of its 'Lyme Disease Experience' survey May 2024.

According to the RCGP Toolkit 'late or missed diagnosis may result in persistent, debilitating symptoms.'

74% were not diagnosed within 4 weeks
31% were not diagnosed for more than 1 year
16% were not diagnosed for more than 5 years.

According to the NICE Guidelines 'Prompt antibiotic treatment reduces the risk of further symptoms developing and increases chance of complete recovery'

69% had difficulty accessing treatment
60% experienced a delay in starting antibiotic treatment of more than 1 month
45% experienced a delay of more than 3 months.
17% experienced a delay of 3 years or more before their first antibiotic treatment

78% did not recover fully after their first course of antibiotic treatment.

61% of those surveyed said that lack of awareness and expertise amongst health professionals was the top barrier to treatment.

Source: Lyme Resource Centre Lyme Disease Experience survey 2024.

Chronic Lyme Disease

Hugely controversial subject

Officially, the NHS doesn't acknowledge that this exists and does not offer treatment.

- Many patients who don't receive the full dose of antibiotics recommended by NICE go on to experience long-term symptoms
- Many patients who DO receive the full dose of antibiotics recommended by NICE go on to experience long-term symptoms
- Many patients who don't get diagnosed and who never receive the correct treatment.

RCGP Toolkit

Risk factors for developing PTLD (post-treatment Lyme Disease) appear to include delay in diagnosis, increased severity of initial illness and the presence of neurological symptoms.
Research into the causes and management of this condition is ongoing

Symptoms of Long-Term Lyme Disease

RCGP Toolkit lists the following symptoms of Late Lyme

- facial palsy
- meningitis
- dizziness
- unexplained radiculopathy
- encephalitis
- neuropsychiatric presentations
- inflammatory arthritis
- neurological conditions
- cardiac problems
- ME/CFS
- fibromyalgia
- uveitis or keratitis
- skin rashes

‘Classic Lyme Symptoms’

Severe, migrating pain
Numbness/tingling
Fatigue
Agitation
Neurological symptoms
Internal ‘tremor’
Shooting ‘ice pick’ pains
Brain fog
Personality changes/mood swings

‘Diagnosis at this stage may be difficult. Negative serology does not exclude the diagnosis.’ RCGP

Horowitz Lyme Questionnaire https://doyouhavelyme.com/online-test-form/

Image by vjohns1580 from Pixabay

The Great Imitator

According to the RCGP Toolkit

‘Symptoms may resemble many other conditions such as facial palsy, ME/CFS, fibromyalgia, polymyalgia rheumatica, MS, motor neurone disease, carditis, meningitis, encephalitis, auto-immune conditions or neuropsychiatric problems.’

If you have long-term health problems and have a diagnosis of ME/CFS, or fibromyalgia, or other long-term condition, please consider the possibility of Lyme Disease

Chronic Lyme

RCGP Toolkit
‘Many doctors and researchers consider that the ongoing symptoms may be driven by chronic infection.

These doctors advocate the use of individualised treatment regimes.

Many patients report significant improvement after treatment with extended treatment regimes and or complementary therapies, although others do not.’

This is reflected in current research which confirms the ability of Lyme to ‘evade’ antibiotic treatment, and for active infection to persist after treatment.
The discovery of ‘round forms’ is particularly relevant.
Different antibiotics are needed to kill ‘round forms’ than spirochetes.
Research shows that people’s symptoms continue because they may still have active infection.

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4876775/
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2774030/

Chronic Lyme Disease

Dr Tania Dempsey

A recent re-appraisal of trials done on Post-Treatment Lyme Disease Syndrome, written by Dr. Brian Fallon from the Lyme and Tick-borne Diseases Research Center at Columbia University, came to the conclusion that there were “benefits of repeated antibiotic therapy for patients with specific chronic symptoms.”

This points to the fact that Post-Treatment Lyme Disease Syndrome is a misnomer. This is not Post-Treatment Lyme Disease Syndrome but rather Chronic Lyme Disease that has not been completely treated. Research in mice and primates has repeatedly shown that the spirochete bacteria that causes Lyme, Borrelia burgdorferi, can continue living in animals despite antibiotic (treatment). A small study was published in April 2018 showing that the same phenomena occurs in humans.

https://drtaniadempsey.com/chronic-lyme-disease-qa/

Chronic Lyme Disease - UK NICE Guidelines

1.3.12 If a person has ongoing symptoms following 2 completed courses of antibiotics for Lyme disease:

- do not routinely offer further antibiotics **and**

1.3.13 Explain to people with ongoing symptoms following antibiotic treatment for Lyme disease that:

- continuing symptoms may not mean they still have an active infection
- symptoms of Lyme disease may take months or years to resolve even after treatment
- some symptoms may be a consequence of permanent damage from infection
- there is no test to assess for active infection and an alternative diagnosis may explain their symptoms.

They go on to say that symptoms may persist, including
•chronic pain
•depression and anxiety
•fatigue
•sleep disturbance.

And suggest referral to adult social care.

Currently in the UK - No treatment is allowed for ongoing symptoms that persist after initial treatment

Statistics - Chronic Lyme

Lyme Resource Centre Research
74% have ongoing symptoms
56% have been unwell for more than 2 years
32% have been unwell for more than 6 years.

Most common symptoms experienced

- Fatigue
- Joint pains
- Muscle aches
- Mood problems
- Sleep impairment
- Impaired thinking
- Memory loss
- Numbness/nerve pain

USA Estimated 2 million people with Post-treatment Lyme Disease – conservative estimate.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6480773/

Figures for the UK not collected.

Between 12-50% of people in UK report long-term symptoms. (The Microbiology Society)
https://microbiologysociety.org/publication/past-issues/life-on-a-changing-planet/article/lyme-disease-in-the-uk-the-continued-rise-of-an-emerging-zoonotic-infection.html

Source: Lyme Resource Centre Lyme Disease Experience survey 2024.

Chronic Lyme

Researchers at Johns Hopkins Lyme Disease Research Centre have identified Post Treatment Lyme Disease (PTLD) as '*a serious and impairing condition', affecting a 'subset of patients who remain significantly ill 6 months or more following standard antibiotic therapy for Lyme disease'*.

"www.MedicalGraphics.de" license (CC BY-ND 4.0 EN).

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4876775/ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2774030/

Treatment Options for Chronic Lyme

- NHS will not offer any treatment for chronic Lyme Disease
- **Long-term Antibiotics with an ILADS-trained doctor - LLMD**
- Many patients seek private treatment with an ILADS-trained LLMD
- ILADS – International Lyme and Associated Diseases Society
- Considered by many to be the best source of accurate, up to date, research-based information on antibiotic treatment of Lyme Disease.
- ILADS recommends individual treatment protocols, based on symptoms, including long-term antibiotics until symptoms resolve.

In the UK, Drs found to be following ILADS treatment protocols risk suspension or being struck off by the GMC.

- https://www.ilads.org/patient-care/ilads-treatment-guidelines/

- **Herbal Remedies**

Napiers. Stephen Buhner Protocol

- Chinese Skullcap
- Japanese knotweed
- Artemisinin – wormwood
- Cryptolepis
- Cistus Incanus
- Cats Claw

- **REMEMBER TO TREAT CO-INFECTIONS**

Lyme Disease and The Immune System

We've seen that Lyme Disease can suppress and confuse the antibody-producing part of the immune system. (Adaptive Immune System)

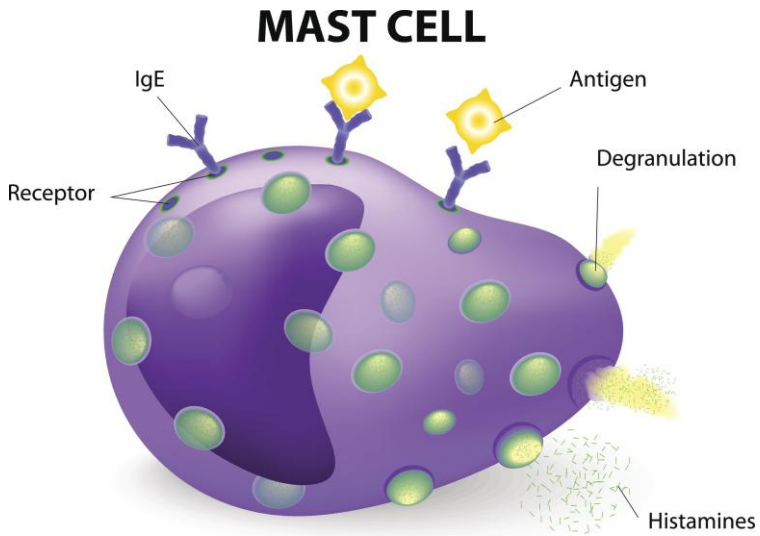
It also causes systemic inflammation (Innate Immune System)

The majority of Lyme symptoms are the result of the inflammation caused in different parts of the body as the immune system tries valiantly to fight the disseminating bacteria.

This is the reason why Lyme symptoms are typically migratory

There are many mechanisms by which Lyme bacteria can trigger autoimmunity, particularly through molecular mimicry, as the host immune system is confused and upregulated by the invading pathogen, which burrows deep into tissue. Daisy Ilchovska https://www.sciencedirect.com/science/article/abs/pii/B9780323991308000416

Alpha-Gal Syndrome – rare reaction causing severe allergy to meat and all animal products



Credit:ttsz Getty Images Istock

Mast Cell Activation Syndrome (MCAS). The Mast Cells can become upregulated by the presence of Lyme bacteria and the toxins they release.

MCAS and Lyme Disease

‘There is a significant subset of patients with Chronic Lyme symptoms who develop a condition known as Mast Cell Activation Syndrome (MCAS). The symptoms of MCAS overlap the symptoms of chronic Lyme disease. There are patients who will just have MCAS alone without any obvious sign of Lyme or other infection, but there will be others who will have had Lyme as a trigger for the MCAS and these patients need to be treated for both…….

Mast cells contain over 200 different chemicals inside them, including histamine, and when they are attempting to fight off something foreign, in this case, Lyme disease, they explode or degranulate, releasing the chemicals causing inflammation.

Of course, if the root cause of what is potentially triggering the mast cells is Lyme disease, then that needs to be targeted as well.’

Dr Tania Dempsey

https://drtaniadempsey.com/chronic-lyme-disease-qa/

Lyme Disease and Mast Cell Activation

‘*Borrelia burgdorferi* Spirochetes Induce Mast Cell Activation and Cytokine Release’ Jeffrey Talkington [1], Steven P Nickell [1,*]

(https://www.ncbi.nlm.nih.gov/pmc/articles/PMC96436/)

According to this study published in 1999 in Infection and Immunity Journal

‘In this study, we show that *B. burgdorferi* spirochetes have the ability to induce degranulation and TNF-α release from’ mouse and rat mast cells

Tick-Borne Disease and Mast Cell Activation

Dr Tania Dempsey 'Many vector-borne diseases, Bartonella included, may trigger MCAS.... Mast cells are one of the body's first lines of defense. When confronted with a pathogen like Bartonella, the cells release a flood of cytokines and other signaling molecules to rally the immune system and neutralize the threat. The problem is that mast cells can become sensitized or hijacked. Your mast cells may be overactive in these cases, continually releasing histamine and/or other inflammatory compounds. Due to the chronic nature of Bartonella, the repeated exposure of mast cells to bacteria creates an environment ripe for MCAS.' **https://drtaniadempsey.com/vector-borne-infections-focus-on-bartonella/**

Dr Bill Rawls 'Signs and symptoms associated with mast cell overactivity are not uncommon in people struggling with chronic Lyme disease. Microbes and other stress factors associated with these conditions disrupt immune system functions and push certain aspects of the immune system, like mast cells, into overdrive.' **https://rawlsmd.com/health-articles/how-to-cope-with-mast-cell-activation-syndrome**

Dr Todd Maderis 'About half of the patients I see with tickborne infections also experience MCAS.'

https://drtoddmaderis.com/mast-cell-activation-syndrome

Lyme Disease and POTS

Dr Dempsey also sees an overlap between Lyme disease and POTS.

She says ‘POTS can be triggered by many different things including infections. Within the category of infections, I have seen POTS triggered by viruses such as Epstein-Barr, bacteria such as Bartonella, Borrelia and Strep, and parasites, such as Babesia.’

https://drtaniadempsey.com/lyme-disease-and-postural-orthostatic-tachycardia-syndrome/

Dr Dempsey says that ‘At least 50%.’ of her patients with Lyme disease have POTS

She goes on to say

I believe that the mast cell component is significant for many Lyme patients with POTS and identifying and treating MCAS can be a game-changer for them.

Chronic Lyme is Complex and Multi-Factorial

Co-infections

- Bartonella
- Babesia
- Mycoplasma
- Yersinia
- Mould illness
- Parasites
- Autoimmunity
- Immune system dysregulation (MCAS)
- Nervous system dysregulation (dysautonomia)
- Nutritional deficiencies
- Tissue damage

All of these interact with one another and vary in each person

Treatment is not straight-forward, and must be individualised for the person

Successful treatment requires all these aspects to be addressed holistically

- Kill bacteria and other pathogens
- Reduce Inflammation and rebalance immune system
- Treat MCAS
- Detox build-up of Lyme toxins
- Repair tissue damage
- Repair gut microbiome
- Replace nutrient deficiencies
- Rebalance nervous system dysregulation

MCAS References

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC96436/

https://pmc.ncbi.nlm.nih.gov/articles/PMC2546763/

https://drtaniadempsey.com/chronic-lyme-disease-qa/

https://drtaniadempsey.com/vector-borne-infections-focus-on-bartonella/

https://drtaniadempsey.com/lyme-disease-the-silent-pandemic/

https://drtaniadempsey.com/lyme-disease-and-postural-orthostatic-tachycardia-syndrome/

https://rawlsmd.com/health-articles/how-to-cope-with-mast-cell-activation-syndrome

Resources

Lyme Disease UK https://lymediseaseuk.com/

RCGP Lyme Disease Toolkit https://elearning.rcgp.org.uk/mod/book/view.php?id=12535

NICE Guidelines https://www.nice.org.uk/guidance/ng95/chapter/Recommendations#laboratory-investigations-to-support-diagnosis

AONM https://aonm.org/

ILADS https://www.ilads.org/patient-care/ilads-treatment-guidelines/

Lyme Disease Action https://www.lymediseaseaction.org.uk/

Caudwell LymeCo https://caudwelllyme.com/

Dr Tania Dempsey https://drtaniadempsey.com/

Dr Rawls
https://rawlsmd.com/health-articles/how-to-cope-with-mast-cell-activation-syndrome

Dr Marty Ross
https://www.treatlyme.net/guide/mast-cell-activation-syndrome-lyme

Dr Todd Maderis
https://drtoddmaderis.com/mast-cell-activation-syndrome

Contacts

Scan the QR Code to subscribe to my Mailing List

Contacts

Website https://livewellwithchronicillness.co.uk/

Facebook https://www.facebook.com/profile.php?id=100088138430749

Instagram https://www.instagram.com/livewellwithchronicillness/

YouTube https://www.youtube.com/@LiveWellWithChronicIllness

LinkedIn https://www.linkedin.com/in/deborah-bircham-08221866/

Email livewellwithchronicillness@outlook.com

Telephone 01780 672505

The End

Thank you for Listening

Any Questions?