



Little is formally documented on the lived experience of Lyme disease - the state of diagnosis, treatment & care and the impact on the lives of those infected. *Lyme Resource Centre (LRC) conducted an online survey to gather information on the impact of Lyme disease in the United Kingdom & Republic of Ireland.*

AWARENESS

Whilst the UK Health Security Agency (UKHSA) offers practical advice on how to protect against ticks & prevent Lyme disease, awareness in some areas of the UK remains low.

311

responses from **residents of UK** who reported being diagnosed with Lyme disease by a qualified health professional; these responses were used for this analysis

54%

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

63%

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

36%

don't recall a tick bite or not sure

25%

were bitten in an urban park, garden or indoors

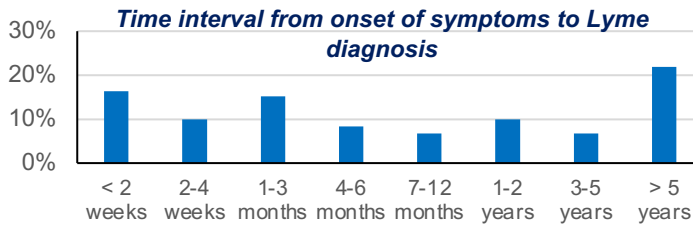
Raising awareness of tick bites and Lyme disease should be a priority

DIAGNOSIS

National Institute for Health and Care Excellence (NICE) guidance on management of Lyme disease *“aims to raise awareness of when Lyme disease should be suspected and ensure that people have prompt and consistent diagnosis and treatment”.*

64%

respondents had an Erythema Migrans (EM) rash



From onset of symptoms

69%

not diagnosed within 4 weeks

39%

not diagnosed for > 1 year

22%

not diagnosed for > 5 years

Timely diagnosis of Lyme disease in the UK must improve

TREATMENT

NICE guidance states that *“Prompt antibiotic treatment reduces the risk of further symptoms developing and increases the chance of complete recovery”.*

80%

had difficulty accessing treatment

11%

did not receive antibiotics

Of the 89% treated with antibiotics

37%

received first antibiotic within 4 weeks and

49%

within 3 months

33%

delay of > one year to first antibiotic, and

24%

delay of 2 years or more

83%

did not fully recover after the first antibiotic course

Prompt, effective treatment for Lyme disease must be available across the UK

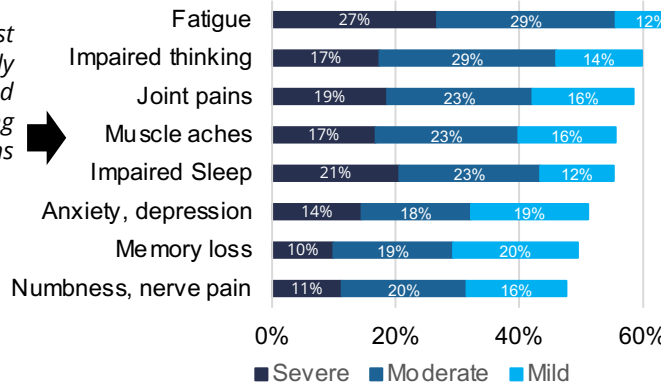
ONGOING NEEDS

NICE guidance also states that *‘Symptoms can be more severe and long-lasting if treatment is delayed’*

78%

have ongoing symptoms

Most commonly reported ongoing symptoms



“The constant pain and fatigue makes me reluctant to do things as I feel so awful afterwards. I miss out on experiences with family and friends.”

“I am unable to work... A lot of people have distanced themselves from me, as they don't understand.”

The UK must meet the needs of those with ongoing consequences of Lyme disease



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AWARENESS

Raising awareness of tick bites and Lyme disease should be a priority

NICE evidence review highlights *“Raising awareness of Lyme disease reduces the possibility that people with Lyme disease are overlooked or not adequately assessed and diagnosed for Lyme disease.”*

SURVEY HIGHLIGHTS A SIGNIFICANT AWARENESS GAP

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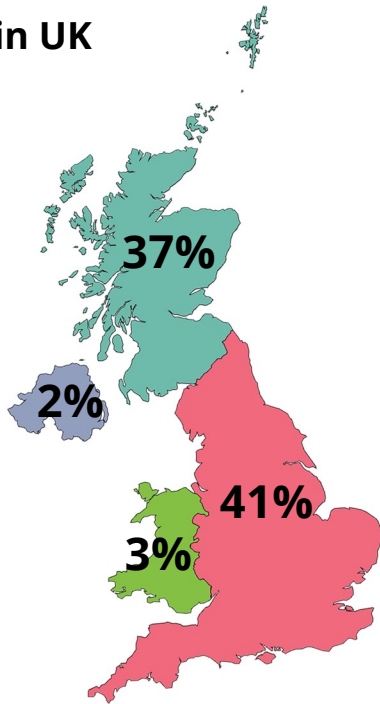
25%

were bitten in an urban park, garden or indoors

Where bitten in UK

83%

respondents reported being bitten at sites within the UK



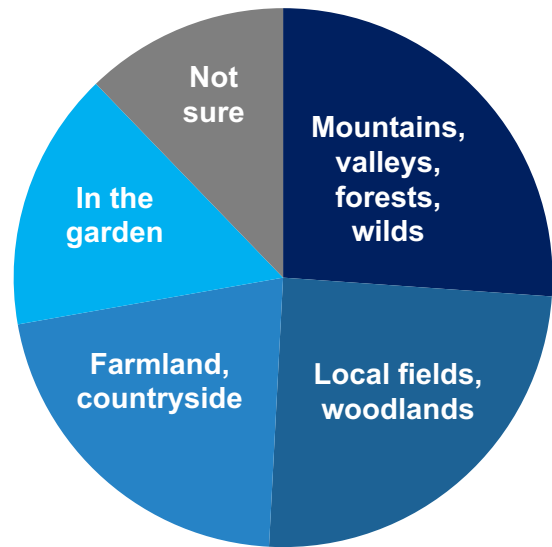
Remaining

17%

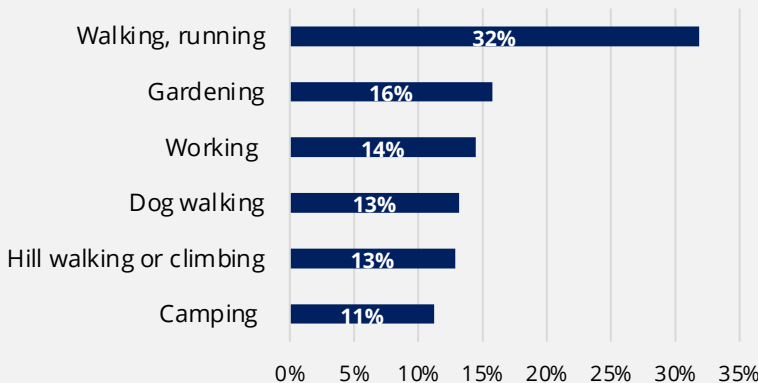
were bitten outside the UK or were unsure of the location

Tick bites occur in everyday places

Top 5 locations when bitten



Top activities when bitten



The UKHSA states

“The best way to reduce the chance of getting Lyme disease is to improve tick awareness, reduce the risk of tick bites and to remove any attached tick quickly and correctly.”

Of those who found & removed a tick

44%

used a recognised tick removal tool



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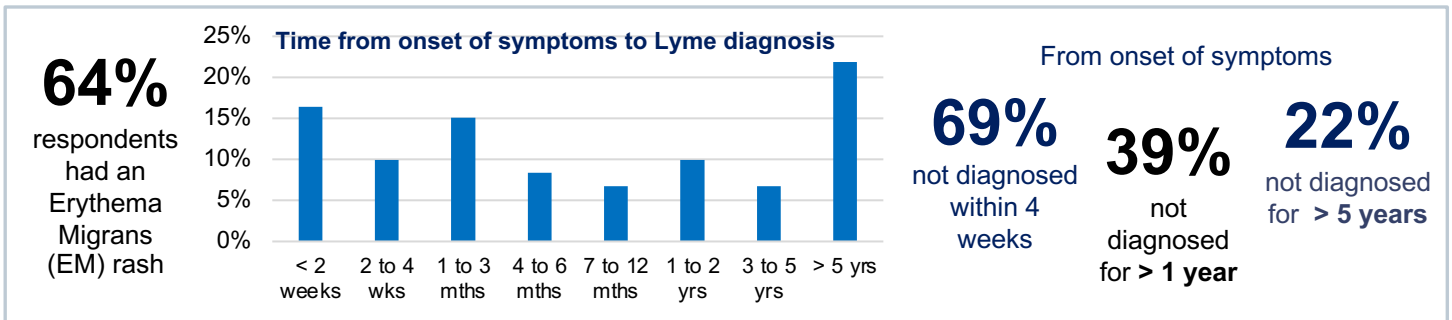
DIAGNOSIS

Timely diagnosis of Lyme disease in the UK must improve

NICE guidance on management of Lyme disease *“aims to raise awareness of when Lyme disease should be suspected and ensure that people have prompt and consistent diagnosis and treatment”.*

The UKHSA states that *“if recognised promptly and treated with a full course of appropriate antibiotics, acute Lyme disease will usually resolve without further complications.”.*

SURVEY HIGHLIGHTS MISSED OPPORTUNITIES FOR DIAGNOSIS



in 80% of responses, self, family member, friend or colleague **first suspected Lyme disease**

Just **4%** respondents diagnosed by an allied health professional

Diagnosis of Lyme disease made by GP for 50% respondents - remainder **diagnosed in secondary care**

People with Lyme disease are seen across a broad range of medical specialisms

12 different recognised secondary care medical specialties made **diagnosis of Lyme disease**

>20 different medical specialties were involved with respondents' Lyme related symptoms

90+ different medical conditions suggested or diagnosed before Lyme disease diagnosis



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TREATMENT

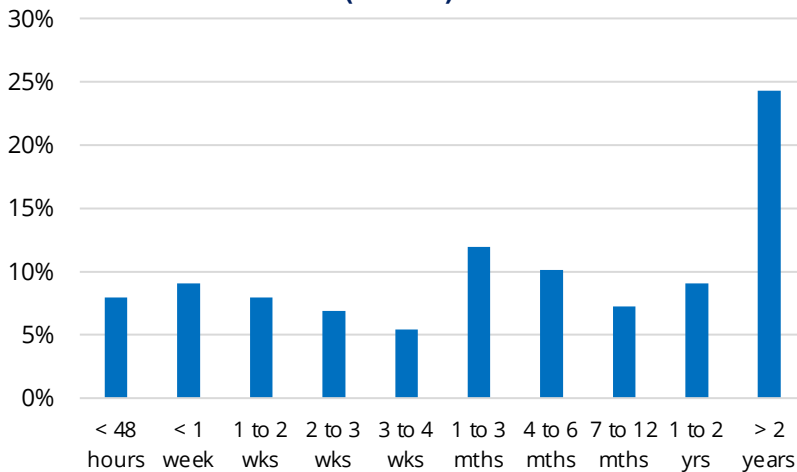
Prompt, effective treatment for Lyme disease must be available across the UK

NICE guideline states that 'Prompt antibiotic treatment reduces the risk of further symptoms developing and increases the chance of complete recovery'.

SURVEY HIGHLIGHTS MISSED OPPORTUNITIES FOR TREATMENT

80% had difficulty accessing treatment	Of the 89% treated with antibiotics	33% delay of > one year to first antibiotic, and	83% did not fully recover after the first antibiotic course
11% did not receive antibiotics	37% received first antibiotic within 4 weeks and	24% delay of 2 years or more	
	49% within 3 months		

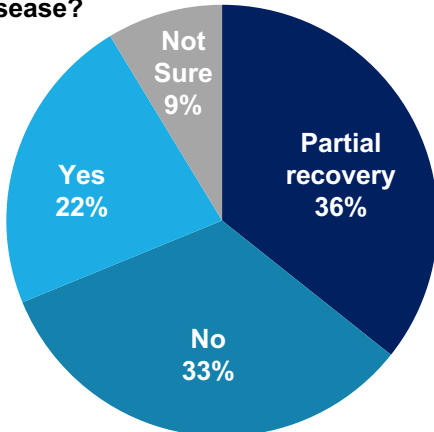
Time from onset of symptoms to first antibiotic (n=276)



"Had to fight - got treatment from GP. Despite having the tick, rash was not bulls eye so not accepted as EM despite having symptoms. When still had symptoms following doxycycline was refused further treatment-- sent tick for testing it was positive. GP contacted ID who stated no further treatment. MSP contacted and intervened on my behalf resulting in full course of amoxicillin in line with NICE guidelines which did resolve symptoms."

Just **22%** have fully recovered

Have you now recovered from Lyme disease?



Of 80% who had difficulty accessing treatment
Key Reasons for Difficulty Accessing Treatment (n=257)

Lack of disease awareness / expertise of health professionals	90%
Misdiagnosis resulting in delayed diagnosis and treatment*	63%
Diagnosis excluded due to negative / inconclusive blood test*	55%
Restrictive treatment guidelines (*despite Lyme symptoms)	53%
Cost of private treatment	52%
Distance to travel for treatment	38%
Stigma associated with Lyme disease	39%

78%
have **not fully recovered** from Lyme disease

74%
have been unwell with Lyme disease for > 1 year

44%
have been unwell for > 6 years



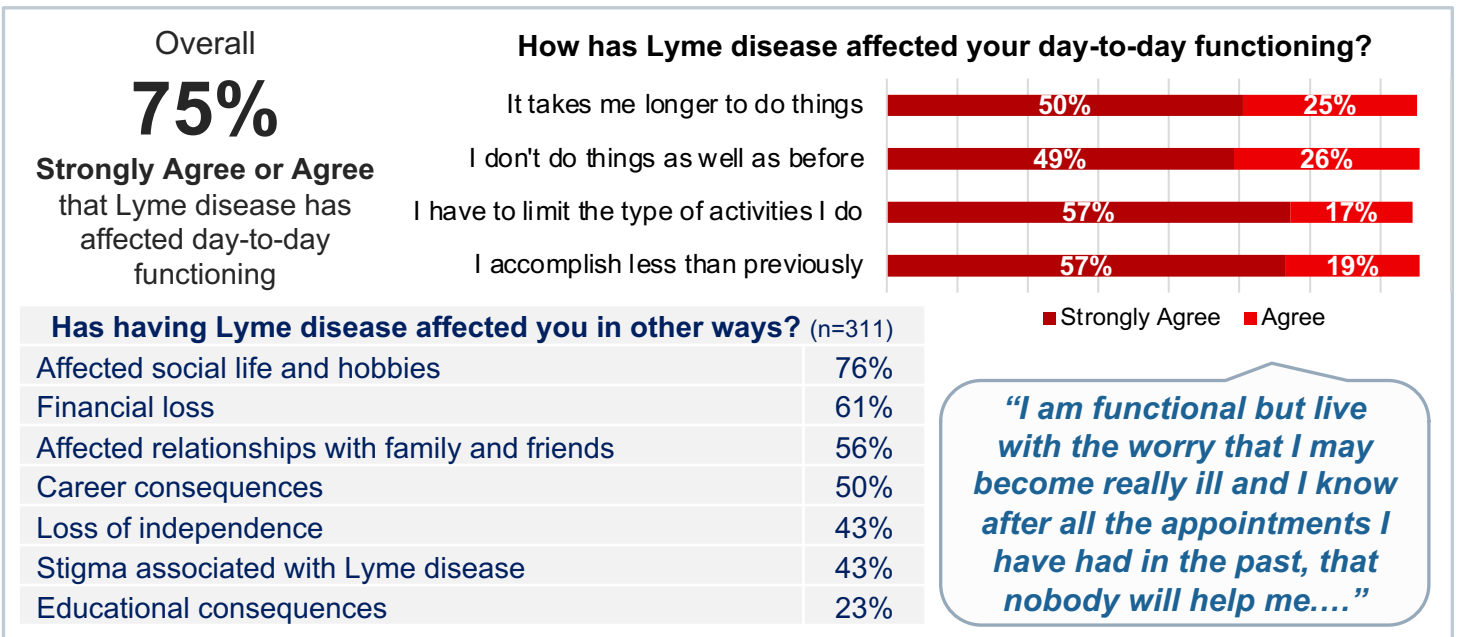
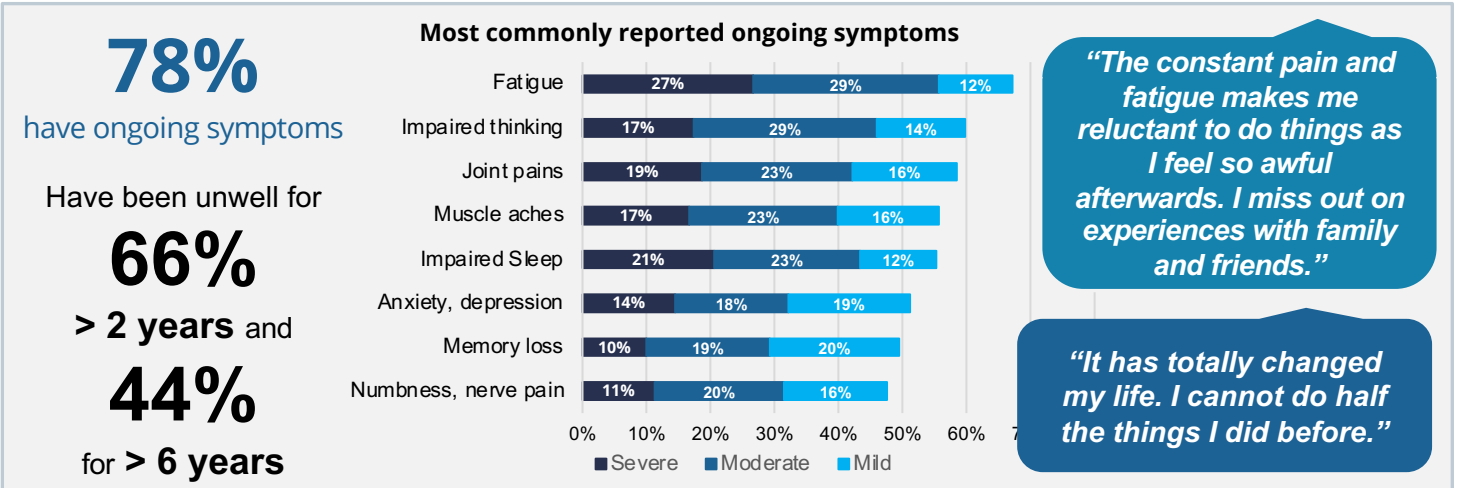
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ONGOING NEEDS

The UK must meet the needs of those with ongoing consequences of Lyme disease

NICE guideline states that ‘Symptoms can be more severe and long-lasting if treatment is delayed’.

SURVEY SUGGESTS SIGNIFICANT ONGOING NEEDS FOR MANY WITH LYME DISEASE



“I am unable to work... a lot of people have distanced themselves from me, as they don't understand. I'm unable to drive. I'm unable to look after my home and garden. I've lost my independence”

“I am not able to work, care for my young family, (even) function for a whole day.”

“It has ruined my life I am not the same person I used to be.”

“(Lyme disease) has significantly impacted every area of my life. Severe restrictions on everything I do. (I am) not house bound but close.”

About Lyme Resource Centre (LRC)

Lyme Resource Centre is a Scottish registered charity (SCIO: SC049151) focused on educating the public and healthcare professionals about Lyme disease & other tick-borne illnesses

<https://www.lymeresourcecentre.com>

About the Survey

From 1st February to 30th April 2024, LRC ran a **Lyme Disease Experience Survey** in UK and Republic of Ireland, to explore awareness of ticks and Lyme disease and *capture the lived experiences of people affected by Lyme disease*, including diagnosis, treatment and health outcomes.

The survey sought to capture responses from people who had fully recovered from Lyme disease as well as those with ongoing symptoms and aimed to drive meaningful change for people who contract and live with Lyme disease and its consequences.

In researching the approach to the survey LRC consulted with the CEO of [MyLymeData](#), a USA based, patient-powered research project with significant experience in surveys and patient data collection for Lyme disease.

Survey Monkey was chosen as the platform for an online survey due to its ease of use, functionality, and cost effectiveness.

Survey Method

To avoid concerns over data privacy and to encourage open, honest responses, the survey was conducted anonymously and participation was voluntary.

Participants were recruited via

- open invitation on the LRC website
- social media channels (Facebook, Instagram, LinkedIn, X [Twitter])
- other organisations including Lyme Disease UK, TickTalk Ireland, Lyme Disease Alba, and others who shared and promoted the survey
- organisations whose members or followers use the outdoors professionally, educationally or socially (e.g. National Farmers Union, Forest Schools Association, Ramblers Association)
- individuals, who raised awareness of the survey with their own networks.

Survey Respondents

Out of 491 completed responses from UK and Republic of Ireland between 1st February 2024 and 30th April 2024, **475 reported a diagnosis of Lyme disease confirmed by a qualified health professional; 311 of these responses were from residents of UK and form the basis of this analysis.** Respondents who could **not** report a diagnosis of Lyme disease by a qualified health professional (including self-diagnosis) were excluded.

Respondents were asked to confirm their answers were accurate to the best of their knowledge prior to submitting their survey response. The large number of completed responses (almost 500) should minimise the impact of any response inaccuracies.

There was no direct access to patients themselves or to any medical records.

We are mindful that some people who fully recovered from Lyme disease may have been unaware of the survey - we aimed to address this by promoting the survey via outdoor organisations.

People with undiagnosed Lyme disease are not represented in this survey.

References

- NICE Guideline [NG95] Lyme Disease <https://www.nice.org.uk/guideline/ng95>
- UKHSA *Lyme disease: Management and Prevention* <https://www.gov.uk/guidance/lyme-disease-management-and-prevention>