

Lyme Disease Experience Survey - All Responses

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.

AWAWARENESS

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

HSE Health Protection Surveillance Centre (HPSC) offers practical advice on how to protect against ticks & prevent Lyme disease

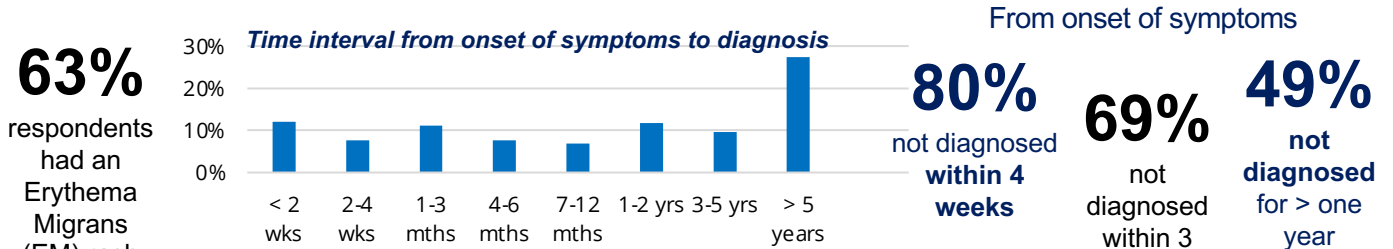


Raising awareness of tick bites and Lyme disease is a priority

DIAGNOSIS

NICE guideline *"aims to raise awareness of when Lyme disease should be suspected and ensure that people have prompt and consistent diagnosis and treatment"*.

HSE Expert Advisory Committee advises early identification of Lyme disease to minimise likelihood of late stage infection.



Timely diagnosis of Lyme disease must improve

TREATMENT

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

HSE Expert Advisory Committee advises prompt and appropriate antibiotic therapy to minimise likelihood of late stage infection.

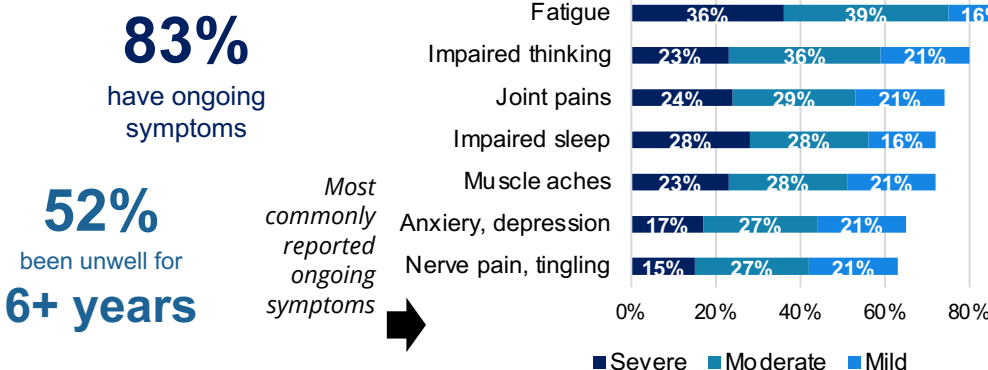


Prompt, effective treatment for Lyme disease must be available

ONGOING NEEDS

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

HSE Expert Advisory Committee advises prompt and appropriate antibiotic therapy to minimise likelihood oflong term complications of Lyme disease.



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

The needs of those with ongoing consequences of Lyme disease must be met



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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 reporting a diagnosis of Lyme disease confirmed by a qualified health professional

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 (via pet)

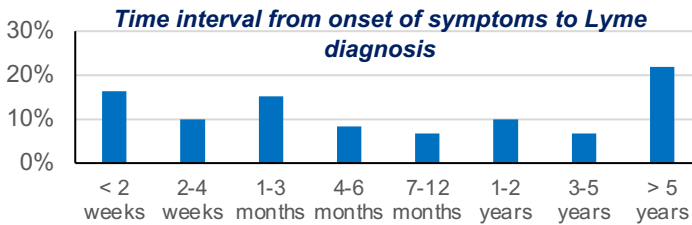
Raising awareness of tick bites and Lyme disease should be a priority

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

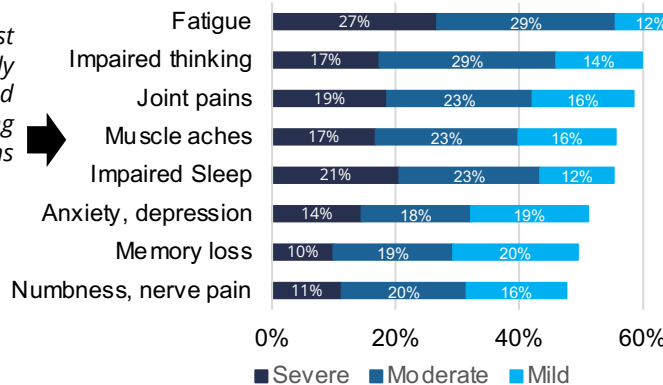
ONGOING NEEDS

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.”

44%

been unwell for

6+ years

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



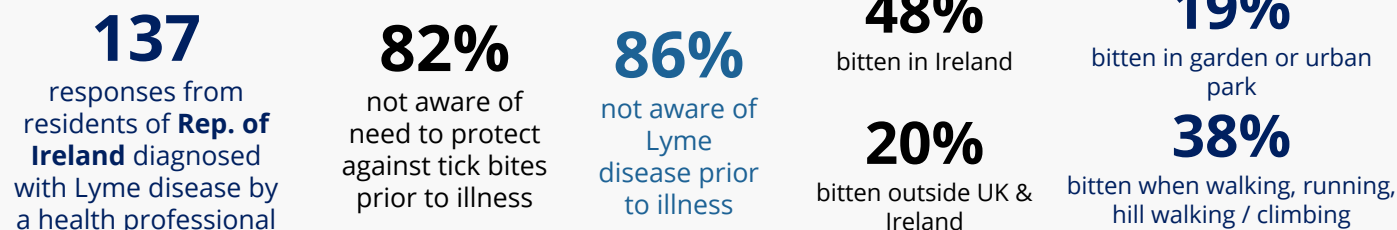
Lyme Disease Experience Survey



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.*

Whilst HSE Health Protection Surveillance Centre (HPSC) offers practical advice on how to protect against ticks & prevent Lyme disease, awareness in Ireland is very low.

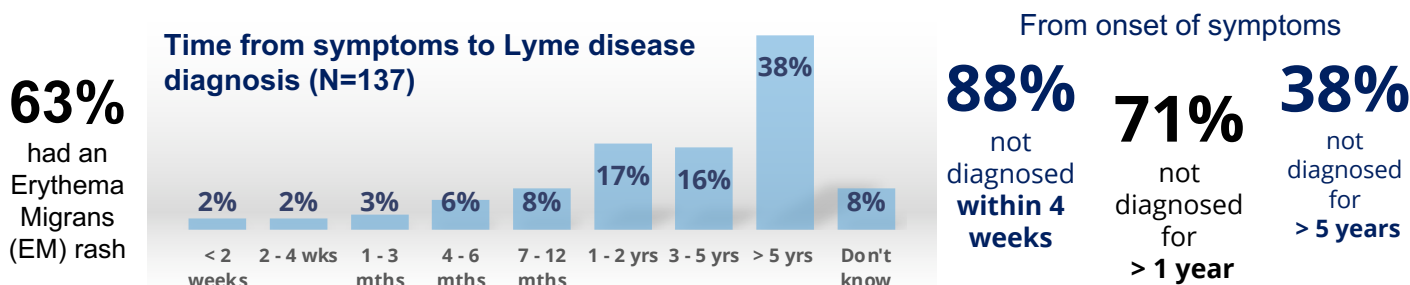
AWARENESS



Ireland must prioritise raising awareness of tick bites and Lyme disease

HSE Expert Advisory Committee advises early identification of Lyme disease to minimise likelihood of late stage infection and/or long term complications of Lyme disease.

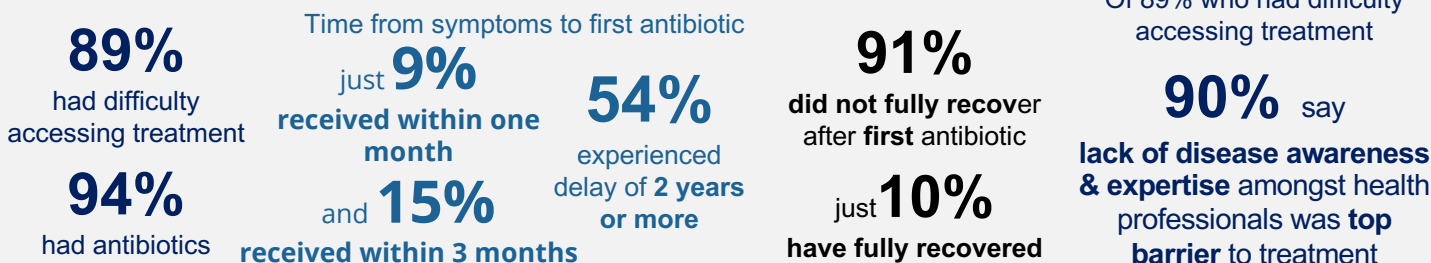
DIAGNOSIS



Timely diagnosis of Lyme disease in Ireland must improve

HSE Expert Advisory Committee advises prompt and appropriate antibiotic therapy to minimise likelihood of late stage infection and/or long term complications of Lyme disease.

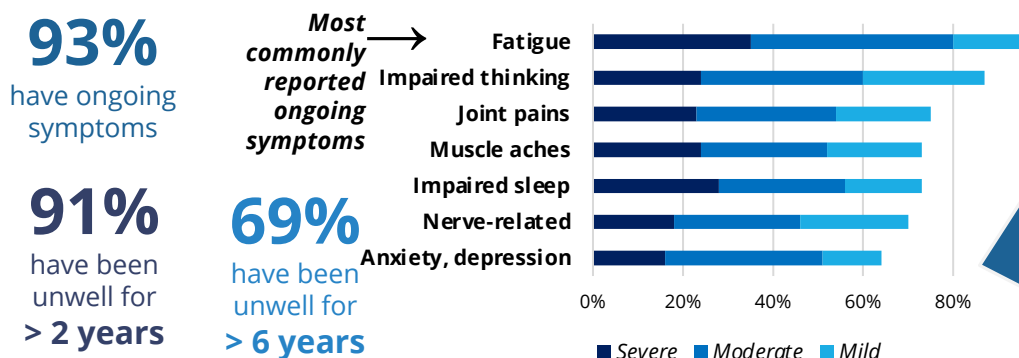
TREATMENT



Prompt, effective treatment for Lyme disease must be available across Ireland

HSE Expert Advisory Committee recognises long-term nature of Lyme disease symptoms but does not provide guidance on management

ONGOING NEEDS



"Lyme means I wake each day feeling just as exhausted as when I fell into bed, it's like a hangover and the worst flu ever on 365 day repeat. I can plan nothing, I lost a glittering career, all of my social circle, my self respect, the respect of others, and all joy. It has been devastating, like a stolen life."

Ireland must meet the needs of those with ongoing consequences of Lyme disease



Lyme Disease Experience Survey



L R C
LYME RESOURCE CENTRE

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

111

responses from **residents of Scotland;** all diagnosed with Lyme disease by a qualified healthcare professional

86%

were bitten in Scotland of which **>80%** bitten in Highlands & Islands

60%

were bitten in local fields, woodlands farmlands **20%** bitten in the garden

33%

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

42%

were not aware of Lyme disease prior to illness

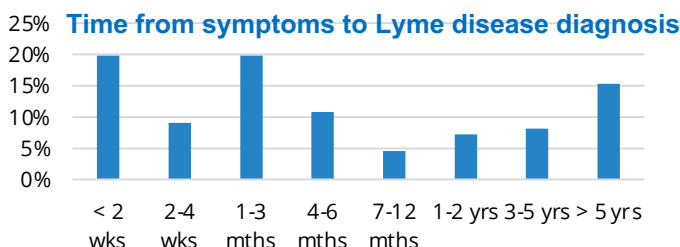
Scotland must prioritise raising awareness of tick bites and Lyme disease

DIAGNOSIS

In a letter of June 2019, Scotland's CMO directs practitioners to NICE guideline 95 on management of Lyme disease, which *"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

71%

not diagnosed within 4 weeks

36%

not diagnosed for > 1 year

15%

not diagnosed for > 5 years

Timely diagnosis of Lyme disease in Scotland must improve

TREATMENT

NICE guideline 95 states that *'Prompt antibiotic treatment reduces the risk of further symptoms developing and increases the chance of complete recovery'*.

68%

had difficulty accessing treatment

Time from symptoms to first antibiotic

57%

delay of > one month

19%

experienced delay of 2 years or more

78%

did not fully recover after first antibiotic

Of 68% who had difficulty accessing treatment,

86%

say lack of disease awareness & expertise amongst health professionals was top barrier to treatment

Prompt, effective treatment for Lyme disease must be available across Scotland

ONGOING NEEDS

NICE guideline 95 also states that *'Symptoms can be more severe and long-lasting if treatment is delayed'*

72%

have ongoing symptoms

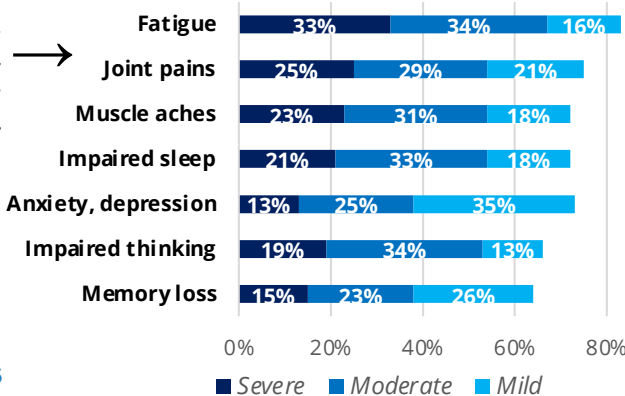
Most commonly reported ongoing symptoms

55%

have been unwell for > 2 years

32%

have been unwell for > 6 years



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

Scotland must meet the needs of those with ongoing consequences of Lyme disease

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 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>
- HSE Expert Advisory Committee - Antibiotic Prescribing - Lyme disease <https://www.hse.ie/eng/services/list/2/gp/antibiotic-prescribing/conditions-and-treatments/skin-soft-tissue/lyme-disease/>
- HSE HPSC advises - Be tick aware, keep you and your family safe from Lyme disease, May 2024 <https://about.hse.ie/news/hse-hpsc-advises-be-tick-aware-keep-you-and-your-family-safe-from-lyme-disease/>