



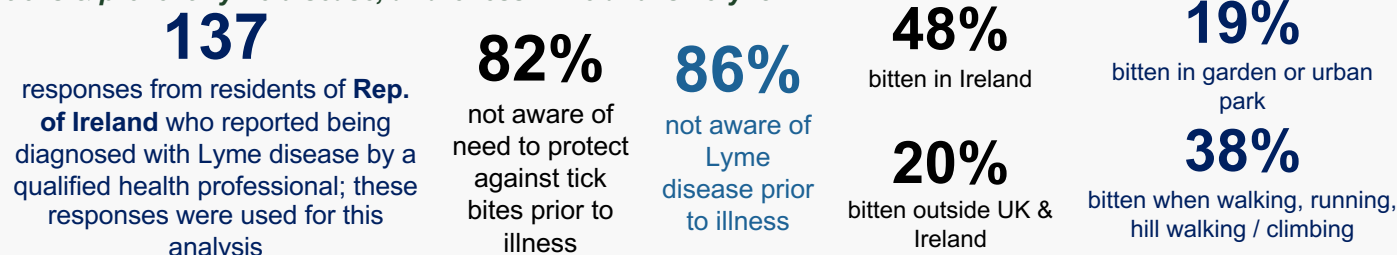
# Lyme Disease Experience Survey



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.*

AWARENESS

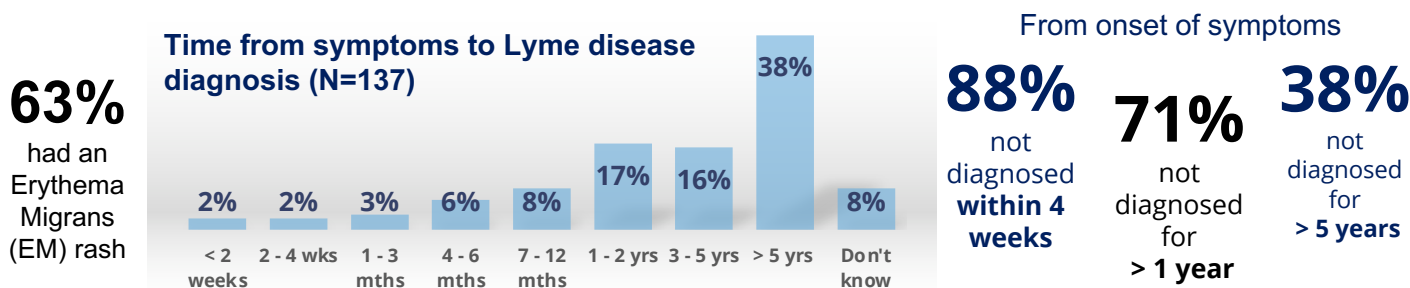
*Whilst HSE Health Protection Surveillance Centre (HPSC) offers practical advice on how to protect against ticks & prevent Lyme disease, awareness in Ireland is very low.*



**Ireland must prioritise raising awareness of tick bites and Lyme disease**

DIAGNOSIS

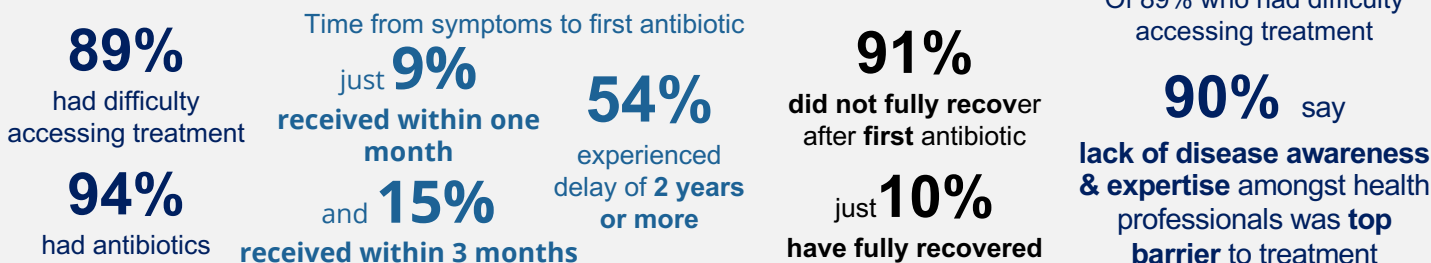
*HSE Expert Advisory Committee advises early identification of Lyme disease to minimise likelihood of late stage infection and/or long term complications of Lyme disease.*



**Timely diagnosis of Lyme disease in Ireland must improve**

TREATMENT

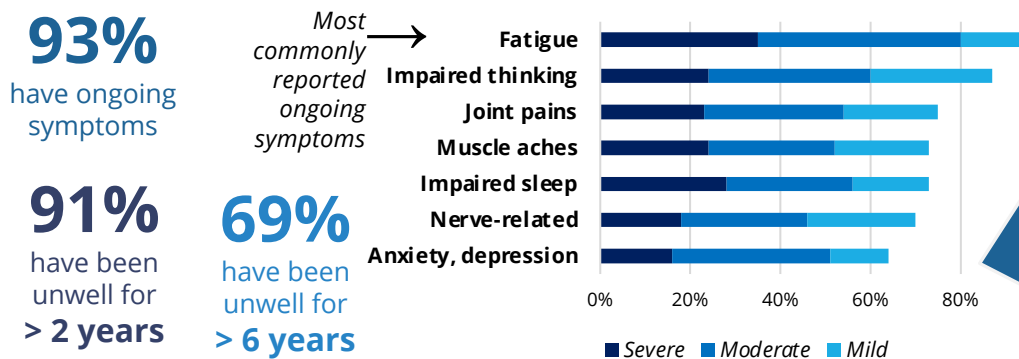
*HSE Expert Advisory Committee advises prompt and appropriate antibiotic therapy to minimise likelihood of late stage infection and/or long term complications of Lyme disease.*



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

ONGOING NEEDS

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



*"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**



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## AWARENESS

### Ireland must prioritise raising awareness of tick bites and Lyme disease

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

<b>137</b>	<b>82%</b>	<b>86%</b>	<b>48%</b>	<b>19%</b>
responses from residents of <b>Rep. of Ireland</b> who reported being diagnosed with Lyme disease by a qualified health professional; these responses were used for this analysis	not aware of need to protect against tick bites prior to illness	not aware of Lyme disease prior to illness	bitten in Ireland	bitten in garden or urban park
			<b>20%</b>	<b>38%</b>
			bitten outside UK & Ireland	bitten when walking, running, hill walking / climbing

#### Distribution of tick bites

The 48% tick bites occurred all over Ireland, but highest in Dublin, Wicklow, Cork, Kerry & Tipperary

Reported tick infection rates of *Borrelia burgdorferi* ranges from 2% - 27% with significant variations between locations, over time (HSE, 2019)

#### Tick bites occur in everyday activities & places

##### Top 5 locations for tick bite / exposure

Top Activities when tick bite / exposure occurred	
Walking, running	24%
Not sure	21%
Hill walking, climbing	14%
Other (e.g. Live rurally, Foraging, Horse-related activities)	13%

**39%**  
can't recall a tick bite

Of those who found and removed a tick, only  
**20%**  
used a tick removal tool

**What could have been better?**

*“Ireland needs resources or a centre of excellence for Lyme so that patients can access information, guidance and support.”*

*“Better awareness on the part of GP's and consultants.”*

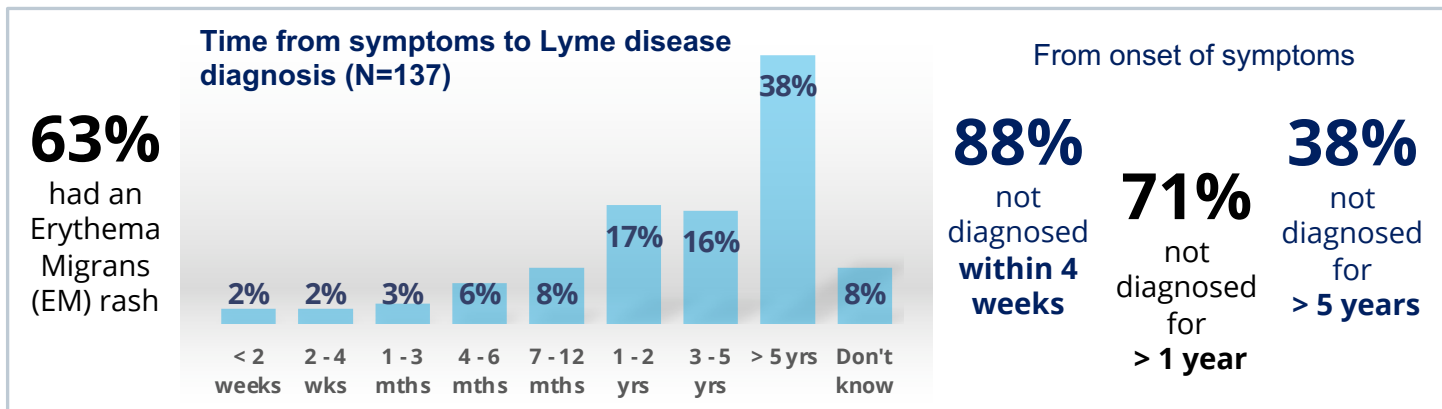


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## DIAGNOSIS

### Timely diagnosis of Lyme disease in Ireland must improve

*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.*



**in 58%** responses, self, family member, friend or colleague **first suspected Lyme disease**

Just **one** respondent diagnosed by an allied health professional

**Diagnosis of Lyme disease made by GP for 18%** respondents - remainder **diagnosed in secondary care**

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

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

At least **20** different medical specialties involved with respondents Lyme related symptoms

**60+** different medical conditions suggested or diagnosed before Lyme disease diagnosis

*"Diagnosis was extremely difficult - it took nearly 3 years."*

*"Lack of correct diagnosis early on led me to suffering immensely for many years."*



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## TREATMENT

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

*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.*

**89%** had difficulty accessing treatment

**94%** had antibiotics

Time from symptoms to receiving first antibiotic –

just **9%** received within one month

and **15%** received within 3 months

Of 94% who had antibiotics

**54%** experienced delay of 2 years or more before first antibiotic

Of 89% who had difficulty accessing treatment

**91%** did not fully recover after first antibiotic

just **10%** have fully recovered

**90%** found lack of disease awareness & expertise amongst health professionals was top barrier to treatment followed by misdiagnosis

**Time from symptoms to first antibiotic (N=129)**

### What could have been better?

*“If Doctor had given me doxycycline when I presented with a bullseye rash which she suspected was Lyme disease, I would have been spared a lot of suffering.”*

*“.....if given antibiotics at the time I might have made a full recovery.”*

*“GP prescribing antibiotics straight away - but was advised by infectious diseases at local hospital to not treat.”*

**85%** did not get first antibiotic within 3 months of onset of symptoms

Just **10%** say they have recovered from Lyme disease

**Have you now recovered from Lyme disease? (N=137)**

**94%** have been unwell with Lyme disease for a year or more

**69%** have been unwell for > 6 years

**93%** have ongoing symptoms related to Lyme disease

**Of 89% who had difficulty accessing treatment**

**Key Reasons for Difficulty Accessing Treatment (N=127)**

Lack of disease awareness, expertise amongst health professionals	90%
Misdiagnosis resulting in delayed diagnosis and treatment	75%
Diagnosis excluded due to negative / inconclusive blood test*	52%
Stigma associated with Lyme disease (*despite Lyme symptoms)	45%
Restrictive treatment guidelines	36%
Cost of private treatment	49%



# Lyme Disease Experience Survey

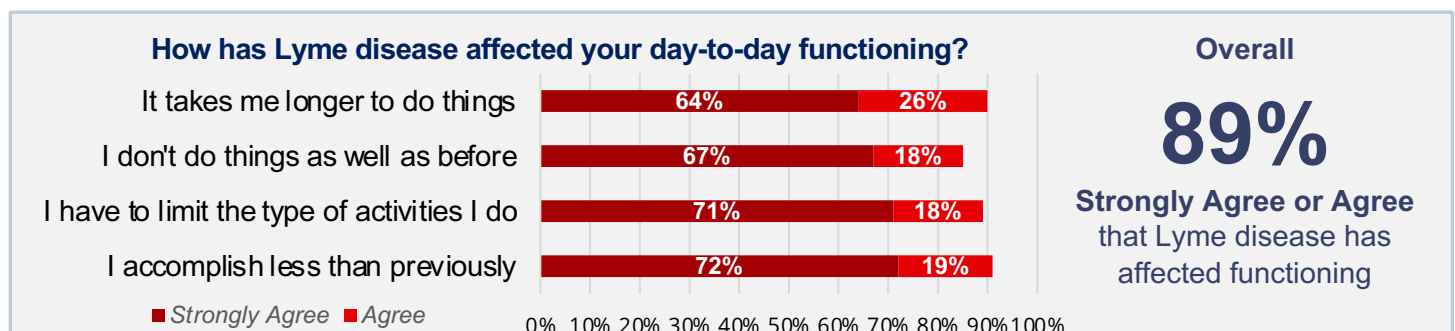
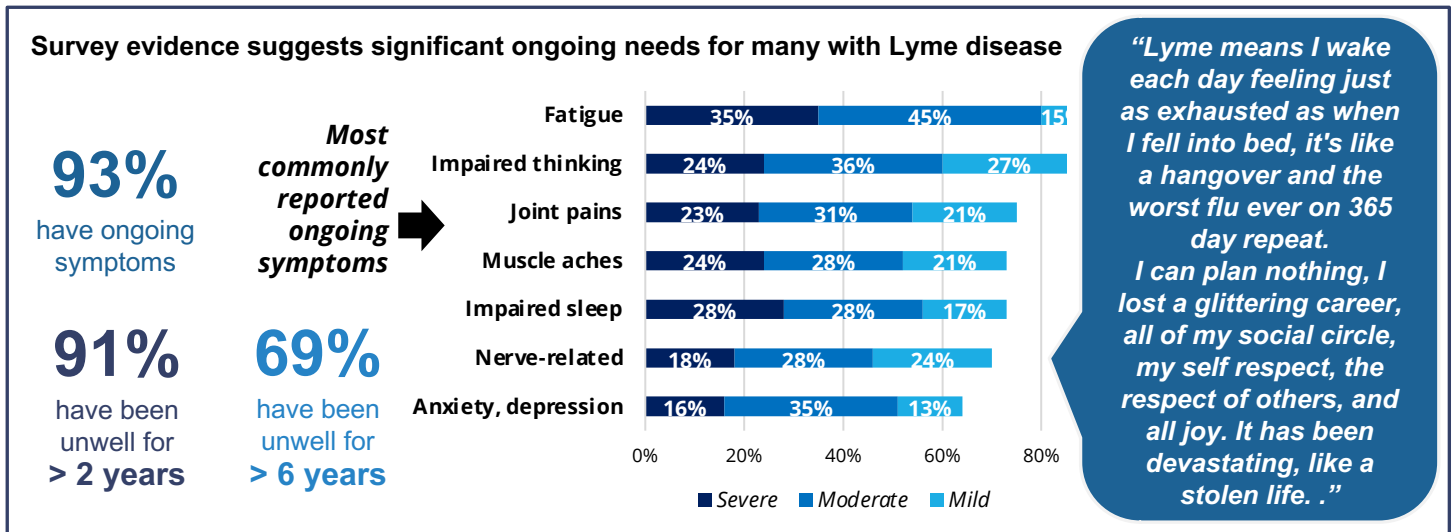


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## ONGOING NEEDS

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

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



**Has Lyme disease affected you in other ways? (N=137)**

Affected social life and hobbies	86%
Financial loss	76%
Affected relationships with family, friends	70%
Career consequences	65%
Stigma associated with Lyme disease	57%
Loss of independence	53%
Educational consequences	30%

*“I had to leave school and am not able to work. It has impacted and interfered with every part of my life. I have no social life no friends and no prospects. Lyme has destroyed my life..”*

*“I went from living wholeheartedly with an interesting career, a busy social life and hobbies to being house bound. I have to plan every activity around my energy....spontaneity is no longer an option and relationships have become increasingly challenging.”*

*“I was a shell of a human being for many years.”*

*“My life will never be the same again....”*

*“My life has changed completely. I am unable to work and have become fully dependent. I spend most of my time at home. I have no energy to accomplish what I’d like to do. My social life is severely curtailed. I can’t drive and travel any longer.”*

## 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 1<sup>st</sup> February to 30<sup>th</sup> 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 aimed to drive meaningful change for people who contract and live with Lyme disease and its consequences. The survey sought to capture responses from people who had fully recovered from Lyme disease as well as those with ongoing symptoms.

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 30<sup>th</sup> April 2024, **476 reported a diagnosis of Lyme disease confirmed by a qualified health professional; 137 of these responses were from Ireland and formed 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

- *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/>
- Primary Prevention and Surveillance of Lyme Borreliosis in Ireland - Report of the Lyme Borreliosis Subcommittee of the Scientific Advisory Committee of the Health Protection Surveillance Centre, October 2019 <https://www.hpsc.ie/a-z/vectorborne/lymedisease/informationforhealthcareprofessionals/Primary%20Prevention%20and%20Surveillance%20of%20Lyme%20Borreliosis%20in%20Ireland.pdf>