



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

108

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

82%

were bitten in Scotland with **>70%** bitten in Highlands & Islands

60%

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

34%

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

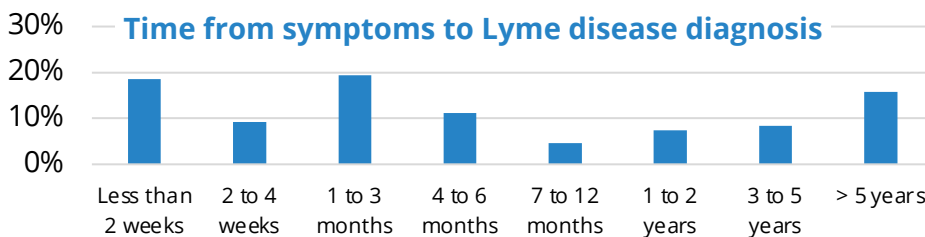
42%

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



74%

not diagnosed within 4 weeks

31%

not diagnosed for > 1 year

16%

not diagnosed for > 5 years

Timely diagnosis of Lyme disease in Scotland must improve

TREATMENT

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

93%

had antibiotics

To first antibiotic

60%

delay of > one month

45%

delay of > 3 months

17%

experienced delay of 3 years or more before first antibiotic

78%

did not fully recover after first antibiotic

61%

found 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 guidance also states that *'Symptoms can be more severe and long-lasting if treatment is delayed'*

73%

have ongoing symptoms

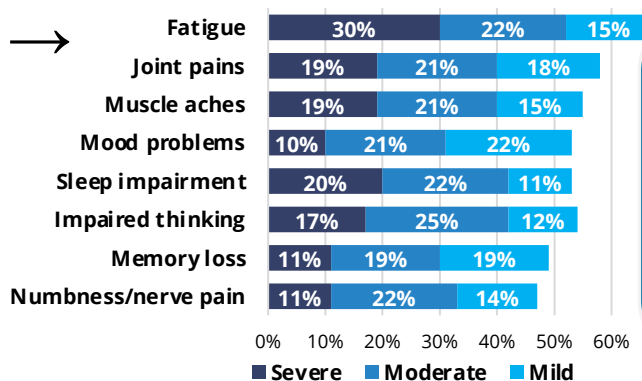
Most commonly reported ongoing Lyme symptoms

56%

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



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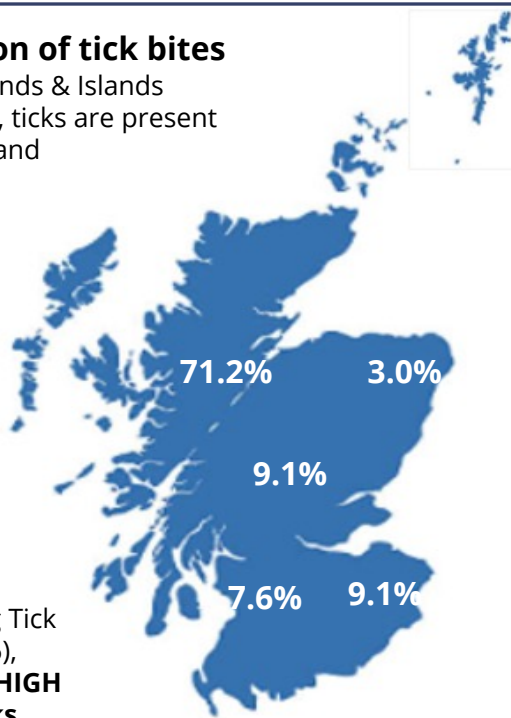
respondents were not aware of need to protect against tick bites prior to illness

42%

were not aware of Lyme disease prior to illness

Distribution of tick bites

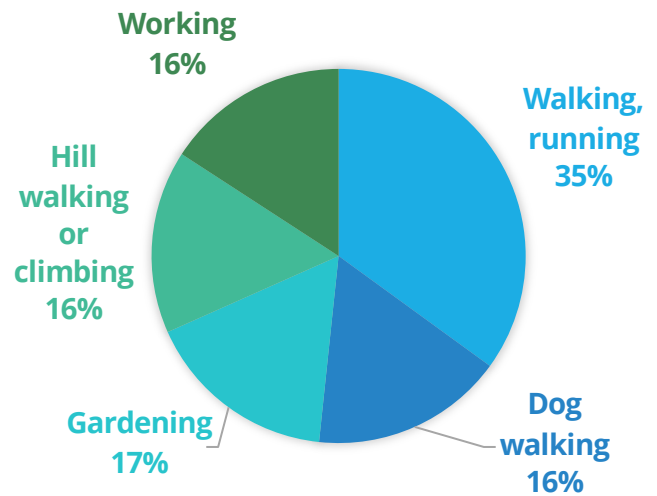
Whilst Highlands & Islands predominate, ticks are present all over Scotland



According to UKHSA & Big Tick Survey (2016), **Scotland is HIGH RISK for ticks**

Tick bites occur in everyday activities & places

TOP 5 ACTIVITIES WHEN BITTEN



Location when tick bite / exposure occurred

Local fields, woodlands	30%
Farmland, countryside	31%
In the garden	20%
Mountains, valleys, forests, wilds	42%
Indoors (i.e. tick exposure via a pet)	1%

30% can't recall a tick bite

Of those who found and removed a tick, only **50%** used a tick removal tool

In a letter of June 2019, Scotland's CMO states - *"Frontline healthcare practitioners have a key role not only in the early diagnosis and management of Lyme disease cases, but also in promoting awareness of ticks and tick borne infections amongst their patients. NHS Boards should promote awareness raising by frontline Healthcare Professionals, including those in Primary Care and GP practices."*

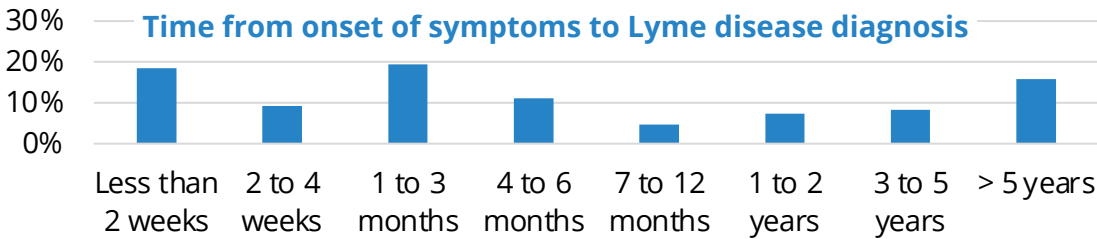


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DIAGNOSIS

Timely diagnosis of Lyme disease in Scotland must improve

In a letter of June 2019, Scotland's CMO directs practitioners to NICE guidance on management of Lyme disease. NICE guidance *"aims to raise awareness of when Lyme disease should be suspected and ensure that people have prompt and consistent diagnosis and treatment"*.



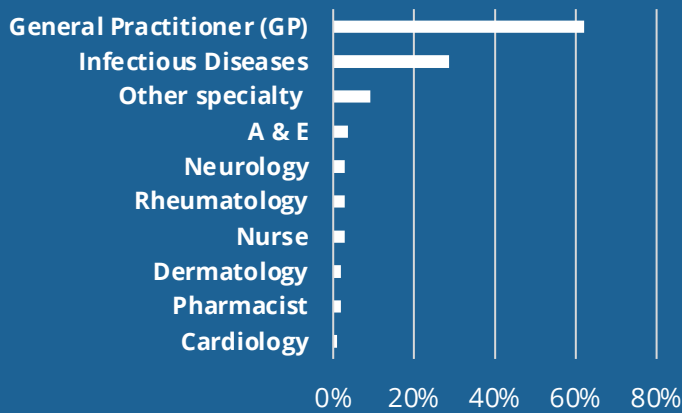
74% respondents were not diagnosed within 4 weeks

31% were not diagnosed for more than a year

The CMO's letter also stated that *"the vast majority of Lyme disease cases can be diagnosed and treated within primary care without the need for specialist input"*.

Survey evidence suggest this isn't consistently happening

Specialty, Role of Diagnosing Professional



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

in **82%** responses, self, family member, friend or colleague **first suspected Lyme disease**

At least **16** different medical specialties were involved with respondents Lyme related symptoms

Prior to Lyme disease diagnosis, respondents had a range of incorrect diagnoses or other medical conditions suggested to them





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TREATMENT

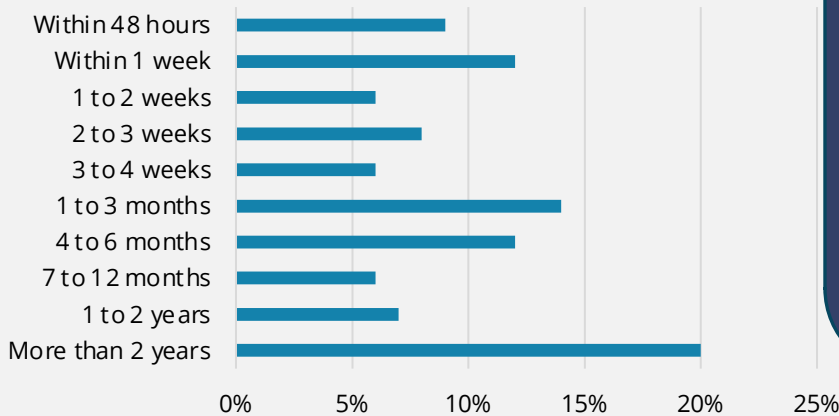
Prompt, effective treatment for Lyme disease must be available across Scotland

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

Survey evidence highlights missed opportunities for effective treatment.

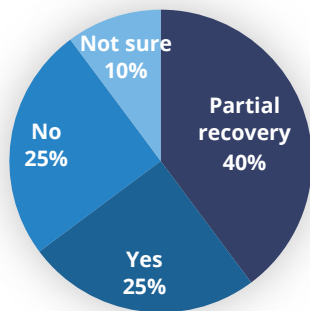
93% had antibiotics	To first antibiotic	17% experienced delay of 3 years or more before first antibiotic	78% did not fully recover after first antibiotic	61% say lack of disease awareness & expertise amongst health professionals is top barrier to treatment
70% had difficulty accessing treatment	60% delay of > one month			
	45% delay of > 3 months			

Time from onset of Lyme disease symptoms to antibiotic



"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."

Have you now recovered from Lyme disease?



Just **25%** say they have recovered from Lyme disease

Key Reported Reasons for Difficulty Accessing Treatment

Lack of disease awareness / expertise of health professionals	61%
Misdiagnosis resulting in delayed diagnosis and treatment	44%
Diagnosis excluded	39%
Restrictive treatment guidelines	34%
Cost of private treatment	31%
Distance to travel for treatment	22%
Stigma associated with Lyme disease	19%

Only **48%** of those with ongoing symptoms were able to access further treatment

68% have been unwell with Lyme disease for a year or more

32% have been unwell for > 6 years



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ONGOING NEEDS

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

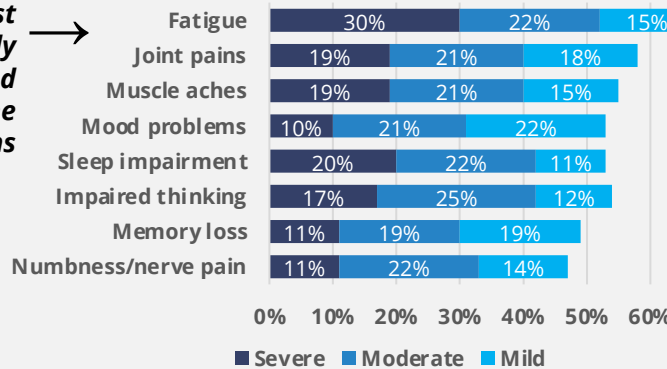
NICE guidance states that *'Symptoms can be more severe and long-lasting if treatment is delayed'*. **Survey evidence suggest significant ongoing needs for many with Lyme disease.**

73%
have ongoing symptoms

Most commonly reported ongoing Lyme symptoms

56%
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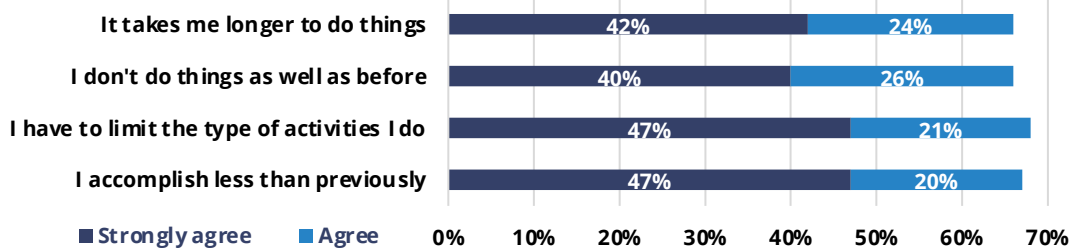
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Lyme disease can have lasting implications & significant consequences

How has Lyme disease affected your day-to-day functioning?



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

Has having Lyme disease affected you in other ways?	
Financial loss (e.g. unable or reduced ability to work, costs of treatment)	50%
Career consequences (e.g. change jobs, reduce hours)	44%
Affected relationships with family and friends	49%
Affected social life and hobbies	69%
Educational consequences (e.g. school absence; leave or postpone a course)	19%
Loss of independence	31%
Stigma associated with Lyme disease, chronic illness	32%

"It's hard to condense how much this has impacted me. I can no longer make plans that cannot be cancelled at short notice, I can't travel abroad.....I have retained a handful of friends who understand what it is like to not have day to day control of my health. I can no longer undertake tasks such as shopping and have a husband who now acts as my carer."

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

What could have been better?
"More awareness of Lyme disease in Scotland and knowledge on how it should be treated and the fact that sometimes treatment doesn't work. Communication between GP and other specialists to be made aware of Lyme diagnosis."