

CDC Says Fewer Suffer After Lyme Disease. Doesn't Say, If Treated Early.

For at least [five years](#), the U.S. Centers for Disease Control and Prevention has officially stated that 10 to 20 percent of patients treated for Lyme disease — some 30,000 to 60,000 of [300,000](#) infected yearly — “will have lingering symptoms of fatigue, pain, or joint and muscle aches,” even after supposedly curative antibiotic treatment.

But quietly, without peer review or formal announcement, the agency has decided that the actual percentage is much smaller — half or a quarter as much. The decision was made, officials told me, based on a [study](#) that showed less than 5 percent of Lyme patients exhibit ongoing symptoms after treatment.

Consequently, the CDC's web site now states that [“a small percentage”](#) of patients will have lingering symptoms of what is called Post-treatment Lyme Disease Syndrome or PTLDS. Other studies have found [higher](#) shares of patients suffering after treatment, particularly when diagnosis is [delayed](#). The study cited by the CDC was of patients treated early and who exhibited symptoms on average 15 years later.

The agency's pronouncement involves the most contentious issue in the debate over Lyme disease: why — and how many — people have problems involving pain, mobility, and mental and physical functioning even after taking single-course antibiotics [recommended](#) by the Infectious Diseases Society of America, or IDSA

In an email, a CDC press officer explained in reference to the new wording: “We changed it based on new information published in 2015 ([Weitzner, et al.](#)) indicating a frequency of <5%, as well as a re-evaluation of the information cited by Marques, from which the 10-20% estimate was originally derived.” When pressed about other studies with different and higher findings, the spokesperson, Candice Hoffman, said the agency was “not relying on a single paper” which might suggest “false precision.” (See CDC's complete answers below.)

Easily treated

Patient advocates say the change is consistent with a CDC pattern to reflect one side of the Lyme research community — the IDSA's — in a way that minimizes persisting symptoms. Weitzner's study, they note, included only patients who are quickly and easily treated; all had the Lyme rash that makes diagnosis straightforward. A recent [analysis](#) of nearly three-dozen studies found that sixfold as many treated patients as in Weitzner's study suffered “residual symptoms.” Emerging research is also showing the Lyme bug's ability to [survive](#)

antibiotic onslaught.

Patients, researchers and physicians worldwide rely on CDC pronouncements on Lyme disease to guide them. The CDC's since-displaced 10 to 20 percent figure for post-treatment problems has been widely [quoted](#) in both [scientific papers](#) and the [popular press](#).

Advocates and scientists say the change was made without notice or transparency. Indeed, while the CDC did not announce the change, the agency's Post-treatment Lyme [web](#) page does not cite the Weitzner study that the press officer referred to but continues to include a citation for 2008 [Marques](#) study, from which the previous estimate came.

The [Weitzner](#) study, published in the IDSA's Clinical Infectious Diseases journal, reported the outcomes of 128 people treated soon after infection and tracked for up to two decades. Six, or 4.7 percent, were considered to have symptoms at their most recent visit, the study said, while 11 percent had "possible PTLDS."

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— Lorraine Johnson,
LymeDisease.org

It is well-known that cases with the so-called erythema migrans rash are easiest to diagnose and, because of early treatment, have better [outcomes](#). On the other hand, an analysis of 34 studies, published in 2015 in the Journal of Neurology, found that [28 percent](#) of patients

suffered continuing symptoms after treatment for Lyme neuroborreliosis, a [disseminated manifestation](#) of Lyme disease involving the nervous system that can cause severe headache, eye problems and facial palsy.

The agency opted not to use a particular percentage in describing the share of people with post-treatment symptoms, CDC's Hoffman said, because numbers vary.

"(V)arious studies have produced various estimates," she wrote in a follow-up to my questions, "and there are serious technical caveats to interpreting each. For this reason, it was felt that providing a specific number (e.g. 10-20) suggested false precision. We are not relying on a single paper - if we were, we would just use that percentage."

'This is not a substantive change. The point of the paragraph is simply to make patients aware that PTLDS occurs.'

— Candice Hoffman, CDC

But other research suggests the share of patients who suffer ongoing problems is not small, experts said, and highly dependent on when treatment is given.

"The way I view the literature is that the studies of early Lyme disease indicate that 5 to 12 percent of those treated early go on to develop ongoing symptoms to 6 months," Dr. Brian Fallon, a Columbia University Lyme researcher, wrote in answer to my questions. "For patients presenting with neurologic Lyme, approximately 25 percent go on to develop

chronic symptoms...(S)o, the outlook is good for patients treated at the time of the rash. The outlook is less optimistic for patients presenting with disseminated neurologic Lyme disease.”

A prominent researcher from Johns Hopkins University agreed that Lyme lingers in cases of delayed care. “There’s lots of studies out there,” said Dr. John Aucott, whose study of early-treated Lyme found an 11 percent rate of ongoing problems. “That one study (CDC officials) are quoting is people who didn’t have delayed treatment.”

Indeed, the CDC’s own web site [states](#) that 70 to 80 percent of infected people get the Lyme rash, leaving some 20 to 30 percent who do not. For this group, treatment is often delayed for months or even years.

No review done

In making the web page change, CDC was failing to abide by the U.S. [Information Quality Act](#), advocates suggested. The act is intended, a federal memo states, to [ensure](#) “the quality, objectivity, utility, and integrity of information (including statistical information) disseminated by Federal agencies.” Further, it applies to web posts involving “scientific information ... (with) a clear and substantial impact on important public policies or private sector decisions.”

The CDC’s Peer Review Agenda web page lists about 50 [reviews](#) performed under the law on such topics as HIV, opioid prescribing and contraceptives. There is nothing listed on its management of Lyme disease, the most common vector-borne disease in America.

“There is no accountability for their content,” said Lorraine Johnson, a published Lyme disease researcher and executive director of LymeDisease.org, a prominent advocacy and research organization. “They are supposed to be disinterested and represent the public. What they are doing is they are representing the IDSA perspective only in a behind-closed-doors process.”

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University researcher

Johnson made a formal complaint to the CDC in 2005, alleging there was a “fundamental lack of transparency and accountability in the information” posted on Lyme disease. She provided an email in which a CDC official rejected her complaint, telling her that the law applied only to “peer review of specific documents,” rather than of all scientific information.

The law did not apply here either, the CDC’s Hoffman, said. “This is not a substantive change. The point of the paragraph is simply to make patients aware that PTLDS occurs,” she wrote.

While other studies challenge the contention that the post-treatment syndrome group is small, even Weitzner’s study states that eight other studies of patients with the rash found rates of symptoms after treatment as high as 41 percent.

A 2005 Oxford University [analysis](#) of five studies found “strong evidence that some patients...have fatigue, musculoskeletal pain, and neurocognitive difficulties that may last for years despite antibiotic treatment.”

Significantly, the Weitzner study had limitations. One hundred and fifty-five people dropped out of the study — patients who on average had one more symptom than the three reported

by the rest of the group, the paper said. “(H)ow this potential selection bias might have affected results is unclear,” states an [editorial](#) that accompanied a separate [article](#) on the research; it was written by Dr. Paul Auwaerter, a Lyme researcher at Johns Hopkins. The editorial, which strongly supported the study, also said it did not show how people responded in the “initial months or early years” after treatment; nor did it include patients with “neuroborreliosis or late Lyme arthritis (who) could answer survey questions differently in the long term.” Nonetheless, the study was labeled a “major article” when published last December.

“This study...is not representative of the true case of Lyme disease patients who have ongoing symptoms,” said Jill Auerbach, a nationally known patient advocate and chairperson of the Hudson Valley (N.Y.) Lyme Disease Association. Of the CDC, she said, “They prefer to minimize Lyme disease; they prefer to make it seem like it doesn’t exist.”

Below are answers provided by the U.S. Centers for Disease Control and Prevention to Mary Beth Pfeiffer’s questions on Post-treatment Lyme Disease Syndrome. The answers were provided by Candice Hoffman, a press officer.

MBP QUESTION: *For about five years at least, CDC was reporting on its web site that “10-20% of patients treated for Lyme disease with a recommended 2-4 week course of antibiotics will have lingering symptoms of fatigue, pain, or joint and muscle aches.” The agency changed that reference in June or July of 2015 to say “In a small percentage of cases, these symptoms can last for more than 6 months.” Can you tell me why the 10-20% figure was replaced?*

CDC ANSWER: *The paragraph concerns the frequency of Post Treatment Lyme disease Syndrome (PTLDS). We changed it based on new information published in 2015 (Weitzner, et al.) indicating a frequency of <5%, as well as a re-evaluation of the information cited by Marques, from which the 10-20% estimate was originally derived.*

MBP FOLLOW-UP QUESTIONS On the procedure: *Regarding the web site change, can you tell me what the protocol is for making such an adjustment? Is there a memo that you could send me that outlines the reasoning behind the change? Should this change have been peer-reviewed under the Information Quality Act, as some experts in Lyme disease believe, since it uses statistical information and affects many people who consult the web site for guidance?*

CDC ANSWER On the procedure: *No; this is not a substantive change. The point of the paragraph is simply to make patients aware that PTLDS occurs.*

MBP FOLLOW-UP QUESTIONS On the data: *Other studies have different outcomes from the Weitzner study. For example, a Johns Hopkins 2013 study by Aucott found a 36% rate of lingering effects after early treatment, while a separate Aucott study, using a stricter definition, found 11%. A meta-analysis of 34 studies of neuroborreliosis found a rate of 28% of lingering symptoms (Dersch, 2015). The Weitzner paper itself states a range of 0-41% in prior studies. Why pick Weitzner when others show different outcomes? Also, why rely on data from early treated patients when it is known that delayed treatment causes additional problems?*

—The PTLDS page now states, “In a small percentage of cases, these symptoms can last for more than 6 months.” However, the Weitzner study states these symptoms were observed a mean of 15 years after treatment. This is far different from six months or more. Should you be more specific? Further, using a 15-year outcome, patient advocates say, leaves out those with symptoms from early years and is a poor yardstick. Your response?

— Can you respond to charges by Lyme disease advocates that this is part of a pattern of CDC minimizing the effects of this disease?

CDC ANSWER On the data: *As listed in the question, various studies have produced various estimates, and there are serious technical caveats to interpreting each. For this reason, it was felt that providing a specific number (e.g. 10-20) suggested false precision. We are not relying on a single paper - if we were, we would just use that percentage. The issue of duration in different studies is moot since we don't provide a specific percentage. We mention 6 months in the sentence because that is the definition of PTLDS.*

Mary Beth Pfeiffer is an investigative journalist who is writing a book, “The First Epidemic,” on the global spread of ticks and the diseases they carry. Follow her on Twitter: @marybethpf

Editor's note: Any medical information included is based on a personal experience. For questions or concerns regarding health, please consult a doctor or medical professional. This article was first published in the Huffington Post.