

ASK A DOCTOR

## What the latest science says about Lyme disease

Up to 25 percent of people develop long-term symptoms after infection. Here's what to do if you're one of them.



Advice by [Trisha Pasricha, MD](#)  
Contributing columnist

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(Washington Post illustration; iStock)

**I've heard so many conflicting things about Lyme disease and what it can do in the long run. What do we really know? What should I do if I get it?**

Lyme disease is a bacterial infection that spreads through [tick bites](#). It may cause flu-like symptoms and a bull's-eye-shaped rash. Most people fully recover after a few weeks of antibiotic treatment.

The hard part is what may follow: Among those who do get antibiotics, anywhere between 10 and 25 percent develop [long-term symptoms](#) — such as fatigue, brain fog or dizziness. Scientists refer to these patients as suffering from “post-treatment Lyme disease” or “post-treatment Lyme disease syndrome,” also known as PTLDS. In 2020, it was estimated that nearly [2 million people](#) suffered from PTLDS.

There are evidence-backed treatments that can help. For example, drugs in a class called neuromodulators, such as nortriptyline, can help with brain fog or pain often seen in PTLDS. But these treatments can take time to have an effect and may involve a bit of trial and error.

“The issue is that there’s probably not one, unifying mechanism — it may be a heterogeneous disorder,” said Paul Auwaerter, a professor of medicine at Johns Hopkins University School of Medicine and former president of the Infectious Diseases Society of America. “It’s been devilishly difficult to figure out.”

It's also important not to miss any important other medical condition that could account for your symptoms. Auwaerter, who has been studying Lyme disease for two decades, said that people have had delays in diagnosis for cancer, ALS and other conditions that had been misdiagnosed as Lyme.

At the same time, he said, doctors should think more about tick-borne diseases and how they can relate to symptoms years down the line. The key is finding a physician you can develop a long-term relationship with.

"It's really important to find someone who takes the time, starts from scratch, does a thorough history and exam, and reviews your prior tests," Auwaerter said. "Then over a series of visits, you work together to find the best diagnosis that can direct care."

### **What do we really know about Lyme disease?**

We've learned so much about Lyme disease over the last five years.

We know that in untreated Lyme disease, the bacteria can spread to other parts of the body, leading to complications like carditis or arthritis. But if the condition is treated, the bacteria generally do *not* evade antibiotics. For example, in one study of 252 patients, in only two patients, or 0.8 percent, did the antibiotics not work; in another study of 225 patients, antibiotics worked in every single case.

But in some patients, scientists now suspect there may be an autoimmune reaction triggered by the initial infection. (Diseases like inflammatory bowel disease or multiple sclerosis may also be triggered by infection.)

In other patients, inflammation triggered by that initial, even if cleared, infection never quite dampens — perhaps because of antigens left behind by the bacteria.

Recent studies have found that PTLDS patients had elevated levels of certain autoantibodies and inflammatory mediators. Patients who had high levels of these markers after antibiotic treatment had a greater than 12-fold risk of developing PTLDS.

PTLDS also may be associated with other conditions, including postural orthostatic tachycardia syndrome (POTS), which causes your heart to beat faster than normal when you transition from sitting or lying down.

We by no means have PTLDS all figured out, but we're getting closer to improving our approach to prevention and treatment. I'm optimistic about the Phase 2 results of a new three-dose Lyme disease vaccine that were recently published in the Lancet Infectious Diseases. The Phase 2 study found that the vaccine was safe, had few side

effects and effectively helped the body create antibodies against the bacteria. Phase 3 clinical trials are underway, and Auwaerter, who is helping lead the trial, expects those results will be available by 2025 or 2026.

Other researchers are building biorepositories of patients who are infected with Lyme disease, tracking blood and urine over time to help understand the mechanisms of why some people develop long-term consequences.

### **Why is Lyme disease so controversial?**

In the past, the ill-defined constellation of symptoms long after infection was called “chronic Lyme disease.” But the Centers for Disease Control and Prevention and others now discourage using the term. Earlier pushback against the name was based on its definition: a persistent microbial infection after antibiotics — which experts argued didn’t exist. This morphed into the idea that the symptoms “didn’t exist” either — and this is where, in the history of medicine, things got ugly.

We’ve seen a similar pattern in the story of long covid — or, before the pandemic, of Epstein-Barr virus — as validated research races to catch up to what patients are feeling. And as in these other cases, people suffering from PTLDS have been long stigmatized.

So let’s remember this: We may debate the cause of an illness and need more research to understand it — after all, that’s the very basis of good science. But someone’s suffering is not imagined.

### **What treatments don’t work for Lyme disease?**

We have fairly sufficient evidence about many therapies that do *not* work for PTLDS. For example, repeated courses of antibiotics are no better than a placebo, an important lesson learned from multiple randomized-controlled trials. This data did not surprise many in the medical community as none of these trials found evidence of residual infection in the first place.

Auwaerter also cautioned against alternative therapies that may be potentially harmful — such as hyperbaric oxygen, chelation or coffee enemas.

### **What I want my patients to know**

Cases of Lyme disease continue to rise with climate change and are spreading geographically. Recent studies estimate that around half a million people in the United States are diagnosed and treated for it every year. That number misses the people who don’t get treatment — and delays in treatment are common, especially among Black patients and people of color who do not always get a stereotypical bull’s eye rash.

<https://www.washingtonpost.com/wellness/2024/06/17/can-lyme-disease-be-cured/>

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tick), we will ask you to submit the tick by mail so we can confirm its species identity.

## Background

Ticks are a nuisance and a public health concern. Ticks are eight-legged arthropods (related to spiders) that need a blood meal from a vertebrate host to complete their life cycle. When ticks blood feed, they can transmit tick-borne diseases like Lyme disease to people and their pets.

There are different species of ticks in Saskatchewan and not all tick species carry tick-borne diseases. For example, the blacklegged tick (*Ixodes scapularis*) can transmit Lyme disease whereas the American dog tick (*Dermacentor variabilis*) can not.

For this reason, it is important to know the species of tick that bit you or your pet. We want to help you identify the species of tick that bit you and provide you with accurate information about the risk of tick-borne diseases.

## Tick species in Saskatchewan

In Saskatchewan, native ticks include *Dermacentor variabilis* (American dog tick), *D. albipictus* (moose or winter tick), and *D. andersoni* (Rocky Mountain wood tick). None of these three tick species transmit Lyme disease. These three *Dermacentor* species have established (self-reproducing) populations in the province of Saskatchewan.

Non-native tick species include *Ixodes scapularis* (eastern blacklegged tick) and *I. pacificus* (western blacklegged tick); both species can transmit Lyme disease. To date, tick biologists have not found any established populations of blacklegged ticks in the province of Saskatchewan (see below for more information on blacklegged ticks).

Other tick species that occur in Saskatchewan are highly specialized on certain vertebrate hosts and therefore rarely bite humans. These wildlife ticks include *I. kingii* (specialized on rodents), *Haemaphysalis leporispalustris* (specialized on rabbits), and *Carios kelleyi* (specialized on bats).

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- About 60 per cent of the submitted ticks came from dogs, then people, then a range of animals including cats, horses, livestock and wildlife.
- Most ticks (*D. variabilis*) were submitted in May and June. However, *I. scapularis* was generally found on pets in the fall (September to November), and occasionally in spring from pets travelling outside the province.
- Very few *I. scapularis* were detected (less than 10 per year) and only one or two tested positive for Lyme disease.

## Ticks and Lyme disease

In North America, there are two species of tick that can transmit Lyme disease:

- *Ixodes scapularis* (eastern blacklegged tick)
- *I. pacificus* (western blacklegged tick)

*I. scapularis* and *I. pacificus* are found east and west of the Rocky Mountains, respectively. In the early 1990s, blacklegged ticks were rare in Canada, but this tick species has dramatically expanded its range in our country over the last 30 years. As a result, the incidence of Lyme disease in the Canadian public has also increased dramatically.








*Ixodes pacificus* (western blacklegged tick). Supplied photo.

In Canada, *I. scapularis* has established populations in southern Manitoba, Ontario, Québec and the Maritime provinces, whereas *I. pacificus* has established populations in British Columbia. To date, no established populations of blacklegged ticks have been found in Saskatchewan.

Where do the blacklegged ticks that bite Saskatchewan residents and their pets come from? One explanation is that migratory birds bring blacklegged ticks from the United States into Canada (including Saskatchewan) each spring. After dropping off migrating birds, these ticks can survive in the environment and bite a person or pet the following year.

Another explanation is that Saskatchewan residents and their pets encounter blacklegged ticks when they travel to an area where these ticks are common.

[https://research-groups.usask.ca/ticks/index.php?~:text=Tick%20species%20in%20Saskatchewan,-In%20Saskatchewan%2C%20native&text=albipictus%20\(moose%20or%20winter%20tick,in%20the%20province%20of%20Saskatchewan.](https://research-groups.usask.ca/ticks/index.php?~:text=Tick%20species%20in%20Saskatchewan,-In%20Saskatchewan%2C%20native&text=albipictus%20(moose%20or%20winter%20tick,in%20the%20province%20of%20Saskatchewan.)

American Dog Tick Cannot transmit Lyme disease	Blacklegged Tick (Deer Tick) Can transmit Lyme disease	 <p>CBC app that identifies ticks ...</p> <p>Wood tick = American Dog tick</p>
 <p>Adult Female</p>  <p>Adult Male</p>	 <p>Adult Female</p>  <p>Adult Male</p>	