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The Unseen Threat of Lyme Disease

A small bite from a tick can have some serious consequences.

BY [SARI HARRAR](#)

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It felt like the flu. Heather Kopsco was tired, achy, and slightly feverish. She also had a rash, which she thought was ringworm picked up at the animal shelter where she worked. But after a week, she still felt lousy. That's when her brother-in-law, a doctor, recognized her rash as the classic bull's-eye caused by Lyme disease.

It made sense. Heather, now 29, had recently been in two places teeming with the deer ticks that carry the Lyme bacterium — Cape Cod, MA, where she and her husband had vacationed, and northwestern New Jersey, where she was doing biology fieldwork.

A three-week course of the antibiotic doxycycline seemed to cure her, but then, as the new school year began, Heather found that her brain was so foggy, she could barely study or work on graduate school applications. "I had to read every sentence twice in order to absorb anything," she says, "so everything took me twice as long."

Worse, Heather had intense joint and muscle pain that seemed to travel from limb to limb throughout her body. During the school year, she took painkillers, put whatever energy she had into her studies and clung to her doctor's reassurance that she would one day recover. Finally, nine months later, she felt better. By then, Heather had also decided what she would study in graduate school: Lyme disease.

Not a Simple Illness

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An unseen tick. An overlooked rash. Misinterpreted symptoms. And, after treatment, a very long recovery. Heather's odyssey matches the new picture of Lyme disease — an infection that, not long ago, seemed relatively straightforward to diagnose and cure. The Centers for Disease Control and Prevention (CDC) estimates there are 300,000 new cases each year in the United States. A whopping 95% are in 13 eastern and upper midwestern states, but the disease is spreading, including to Canada and the Pacific coast.

If the infection is caught early enough, it can usually be cleared up in a few weeks with antibiotics. But unchecked, it can cause joint pain and arthritis, meningitis, facial paralysis, and other problems. In 2012 and 2013, untreated Lyme even led to three heart-related deaths.

Treating Tricky Symptoms

The best-known sign of Lyme is a target-like rash (see [CDC.gov](http://www.cdc.gov) for an image) that appears anywhere from three to 30 days after a tick bite. But not every patient gets one, says John Aucott, M.D., an infectious-diseases specialist in Lutherville, MD, and founder and president of the Lyme Disease Research Foundation. And you may not notice a rash if it's small or if it crops up on your back, behind your knees or on your butt. Also, the rash can be simply a round or oval red blotch and may not necessarily appear where you were bitten.

Other early signs of infection include the chills, fatigue, fever, and joint and muscle aches that Heather suffered. Your doctor should do a full-body check if you have symptoms, even if you haven't noticed a rash, says Lyme researcher Gary Wormser, M.D., chief of infectious diseases at New York Medical College. Blood tests, which detect antibodies to the bacterium that causes Lyme, often miss the infection in the first several weeks as the immune system mounts its defense. That's why, even with a negative test, if you've been bitten by a deer tick or have symptoms and have been in a Lyme area, your doctor might start you on antibiotics. At the other extreme, some people are diagnosed very late, after months or even years. So if you think you may have Lyme but have never been diagnosed, ask your doctor for a test.

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If Your Illness Persists

Roughly 10% to 20% of patients still don't feel well after treatment and continue to experience fatigue and muscle or joint pain, as Heather did. Understandably, they can become frustrated — by illness that never seems to go away and by medicine's seeming inability to help them feel well.

At one time, doctors wrote off these complaints as unrelated to Lyme, but today that cluster of symptoms has a name: post-treatment Lyme disease syndrome. Many experts suspect it is the result of damage to tissue and the immune system from the original infection. Pain relievers, adequate sleep, a healthy diet, massage, and light exercise may help with recovery.

Other doctors, however, believe that many patients have an ongoing infection (often called chronic Lyme) and can benefit from long-term antibiotics — an approach that neither the CDC nor the Infectious Diseases Society supports, in part because of the potential risks of such treatment. It's become an extremely heated controversy, with each side pointing to research that supports its views.

But one thing all agree on is the urgent need for more studies. Lyme was only discovered in the mid-1970s, with the connection to the deer tick not established until 1981. "It is still a relatively young disease, and we have a lot to learn about it," says Dr. Aucott. "Figuring out why some people have ongoing symptoms and how to help them depends on rigorous research."

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Where Lyme Lurks

The disease is most concentrated in these states: Connecticut, Delaware, Maine, Maryland, Massachusetts, Minnesota, New Hampshire, New Jersey, New York, Pennsylvania, Vermont, Virginia and Wisconsin.

But Lyme isn't the country's only tick-borne disease: At least 10 other infections are carried by a variety of ticks across the U.S., causing everything from chills and fever to kidney failure and even death. Lyme patients are sometimes coinfecting with another of these diseases. This can make diagnosis trickier and magnify symptoms, and it may call for different treatment.

Photo: Heather Kopsco

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