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Health

Chronic Lyme Disease Was Once Dismissed. More Doctors Are Coming Around.

Newer trials are starting to track Lyme patients and investigate potential treatments

By Brianna Abbott
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When Gretchen Dunoyer heard that the Massachusetts Institute of Technology was recruiting people with lingering Lyme disease symptoms for a study, she burst into tears.

Dunoyer, 63, had near-constant fatigue and vertigo for years, after an odd, flulike illness in the summer of 2002. She bounced around from doctor to doctor looking for answers. Many of them told her that she was depressed, but she had a gut feeling that something else was wrong. Around 2015, she was told the root of her distress was likely Lyme disease, courtesy of a tick bite that she didn't remember.

Dunoyer spent the next decade cycling through unproven treatments, at times still navigating pushback from some doctors.

Then, MIT started recruiting people just like her. The feeling of validation was overwhelming. "Just not to be marginalized anymore was huge," said Dunoyer, who lives in Watertown, Mass.

Long contentious, chronic Lyme, as it is called by patient advocates, has gained more acknowledgment and investment by researchers after Covid-19 showcased how an infection can leave people with lingering symptoms that last months or longer. The virus's aftermath looked strikingly similar to what some Lyme disease patients had been describing for years.

"People had a real-life illustration of how an infection triggers a syndrome," said Dr. John Aucott, director of the Johns Hopkins Lyme Disease Clinical Research Center, who has studied the condition for two decades. "That helped a lot with acceptance."

Health officials often call it Post-Treatment Lyme Disease Syndrome, defined as having prolonged symptoms such as persistent fatigue and pain for at least six months after a treated Lyme infection. A 2022 study published by Aucott found that 14% of early diagnosed and treated Lyme patients they followed met the criteria. As a comparison, the team also tracked people

without a history of prior infection, and 4% of them had similar symptoms.

“Frankly, our work has shown that it’s real,” Aucott said.

In May, the National Academies of Sciences, Engineering and Medicine published a report saying that research funders should put more emphasis on developing treatments for patients with lingering symptoms after Lyme disease, even as the root cause behind why patients experience the symptoms remains a mystery.

Doctors have debated for decades about whether the condition is real, what causes it and how to treat it. Part of the problem, researchers said, is that fatigue, muscle aches and brain fog are vague enough that any number of diagnoses including fibromyalgia, long Covid or even cancer could be the true cause of a patient’s distress. Some patients who suspect their symptoms are linked to Lyme are later diagnosed with other, sometimes treatable conditions. Others have their symptoms dismissed or never get a firm diagnosis.

To get Lyme disease, a person needs to be bitten by a bacteria-carrying tick. Blacklegged ticks carry the bacteria in the eastern U.S., with most cases occurring in the Northeast, mid-Atlantic and upper Midwest. Their reach is expanding thanks to growing deer populations and a warmer, wetter climate. The western blacklegged tick also transmits the infection along the Pacific Coast.

Ticks are most active from April through September, but exposure can happen year-round. And this year appears especially bad.

The bacterial infection can lead to a telltale bull’s-eye rash, muscle aches and more serious complications including Lyme-related arthritis or facial paralysis if left untreated. For most people, a two- to four-week course of antibiotics successfully cures the disease.

But an estimated 5% to 20% of people develop prolonged and sometimes debilitating symptoms even after treatment, including fatigue, pain and cognitive problems. The risk of lingering symptoms increases if a person’s diagnosis and treatment are delayed, data suggests.

Blood tests can help determine whether a patient has antibodies against the pathogen but can’t tell if persistent symptoms are related or if the person has an active infection. And there are no treatments that have been proven safe and effective for lingering symptoms after the initial antibiotics, researchers said.

“We’re exactly where we were when I first started,” said Dr. Linden Hu, an infectious-disease doctor and co-director of the Tufts University Lyme Disease Initiative, who has been studying lingering Lyme symptoms for decades. “We still have no diagnostic test. We still have no treatment.”

The National Institutes of Health and other agencies have started to take the condition more seriously in recent years, Hu said. In an NIH-funded trial, Hu’s team is recruiting 1,000 Lyme disease patients in New England with a recent diagnosis to follow them over time, anticipating

that some of them will develop prolonged symptoms. The team is collecting bacterial and microbiome samples and tracking immune responses.

The NIH also announced funding for several other research projects looking into prolonged Lyme symptoms and the potential causes in 2023, including for work being done at MIT.

Dunoyer signed up for the MIT trial in spring 2024, and her husband joined as a healthy participant. The pair had their blood drawn and sweat, saliva and urine collected, took neurological tests and underwent a test to evaluate blood flow to the brain, which Dunoyer couldn't finish because she got nauseous and felt like she was going to pass out. The experience drained her for the next week, but she is glad she participated, she said.

"What we're trying to do is measure everything," said Michal Caspi Tal, an immunologist at MIT, who is leading the study, which also includes acute Lyme and long Covid participants. "I want to find a way to give people hope."

Some laboratory researchers are investigating what might be behind the symptoms, including whether a molecule that the bacteria left behind could be driving inflammation. Newer trials are now looking at whether certain antibiotics or electrical nerve stimulation might help treat the condition, since persistent infection and immune-system or neural-network dysfunction are also theories doctors have proposed. Prior trials haven't found a benefit to more antibiotics after initial treatment.

"We're not just focusing on one mechanism but many different possible mechanisms as to why people might have persistent symptoms," said Dr. Brian Fallon, director of the Lyme and Tick-Borne Disease Research Center at Columbia University and head of the Lyme-focused clinical trial network that launched in 2021.

Preventing tick bites remains a person's best defense against Lyme and other tickborne diseases. People should avoid wooded and brushy areas with high grass, walk in the center of trails and cover up extremities, health officials say. Wearing insect repellent, checking your body for ticks and showering soon after being outdoors also help reduce the risk.

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