

What It's Like to Live With a Tick-Borne Disease

Chronic pain, fatigue, rashes: As tick territories are expanding, so too are the number of illnesses they cause.



By Dana G. Smith

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When Reema Shah was 13 years old, she became plagued by a mysterious suite of symptoms: rashes, brain fog, fatigue. Her exhaustion was so extreme that walking up stairs would leave her winded, and she had to quit her high school tennis team; she could barely even keep up with her schoolwork.

In her hometown of Hillsborough, N.J., doctors diagnosed her with allergies and eczema and prescribed steroids and antihistamines, but none of the treatments helped.

In the years that followed, Ms. Shah's symptoms would wax and wane. The rashes gave way to severe joint and muscle pain and inflammation, first in her legs and hips, then in her neck and jaw. Physical therapy helped with her pain and mobility, but she still "didn't have the right diagnosis, the right understanding, the right treatment for why this was happening," said Ms. Shah, who is now 28 and lives in New York City.

It wasn't until her vision began to deteriorate at age 27 that the pieces finally clicked into place. An eye doctor diagnosed Ms. Shah with uveitis — inflammation inside the eye — which can result from an infection or autoimmune disease. So she saw a rheumatologist who ordered multiple blood panels; the one for Lyme disease came back positive.

Given that she grew up in an area that was a hotbed for ticks, perhaps her diagnosis should have been obvious based on her early symptoms. But back then, "a lot of us were still not as educated on tick-borne diseases," she said. And because her later symptoms kept affecting different organ systems, none of the specialists she saw connected the dots.





Elizabeth Bonitz tries to preserve all of the ticks she pulls from her body, taping them to a notecard so she can share them with medical professionals as needed. Kate Medley for The New York Times

The rheumatologist wrote her a prescription for the antibiotic doxycycline, which is used to treat various tick-borne diseases. But now, nearly two years later, many of her symptoms, particularly the chronic pain, remain.

“It’s gotten a little bit better, but I’m not anywhere near where I want to be yet in terms of quality of life improving significantly,” Ms. Shah said.

Lyme disease

According to the Centers for Disease Control and Prevention, tick-borne diseases are becoming increasingly common. Between 2011 and 2019, for instance, cases rose by 25 percent. That is in large part because of expanding tick territories thanks to migrating deer and mice populations.

“We’re now seeing more cases of everything,” said Dr. Bobbi Pritt, a pathologist and clinical microbiologist who specializes in parasites at the Mayo Clinic. This includes not only Lyme, but other tick-borne infections that used to be rare, like babesiosis.

“We basically have tick-borne diseases almost everywhere,” in the United States, Dr. Pritt said. But individual tick species and the diseases they carry vary by region.

Lynley Smith, 43, knew about the heightened risk of Lyme disease in Maine when she vacationed with her family there last summer. On the final day of her trip, she started feeling fatigued and achy, especially in her neck. When she returned to her home near Baltimore, she requested a test for Lyme at a local health clinic, but it came back negative.

Over the next few days, Ms. Smith felt progressively worse. Her primary care doctor said it was probably just a virus. But two days later, the pain in her neck became so severe that she visited the emergency room. A doctor there asked if she had a rash, which is often used to identify Lyme, but Ms. Smith hadn’t seen one. So he also told her it was most likely a viral infection and sent her home.

On the seventh day of her symptoms, Ms. Smith noticed a large, round rash on the right side of her torso. By that point, she said, “I felt so uncomfortable in my body that I couldn’t even sit still.” She returned to the health clinic — her fourth doctor’s visit in a week — and finally got a Lyme diagnosis based on her symptoms. She was prescribed two weeks of doxycycline; it took a month for her to feel like herself again.

“I’m lucky that even though it was hard to diagnose, as far as I know, my body is rid of it,” Ms. Smith said.



Tom Termer, 64, developed an allergy to red meat after being bitten by a tick. Symptoms can include hives, gastrointestinal distress and, in more severe cases, low blood pressure and anaphylactic shock. Lawren Simmons for The New York Times

Lyme is by far the most common tick-borne disease, afflicting an estimated 300,000 people each year, according to the C.D.C. It is transmitted by the blacklegged, or deer, tick, which is most prevalent in the northeast and upper Midwest but is spreading south. The ticks are most active between spring and fall, and Lyme cases tend to peak during June and July, though it is possible to get bitten year-round.

Initial symptoms of Lyme typically include fever, chills, fatigue, headaches and achiness. A round, reddish rash appears in roughly 70 percent of cases, but it often doesn't look like the bull's-eye people think of, said Dr. John Aucott, director of the Lyme Disease Clinical Research Center at Johns Hopkins University.

Without a rash, Lyme can be challenging to identify because its early symptoms are similar to those of many other infections. A blood test can detect antibodies the immune system makes in response to the bacteria that causes it, but those tests often don't come back positive for several weeks.

If untreated, the infection can travel through the bloodstream and infect other tissues in the weeks and months after the tick bite. In rare cases, people can develop meningitis (an inflammation of the protective membranes around the brain and spinal cord) and Lyme carditis (which occurs when the bacteria infect the heart tissue and can cause an irregular heartbeat). In about 60 percent of untreated Lyme cases, the disease spreads to the large joints, especially the knees, and causes painful inflammation and swelling, called Lyme arthritis.

When doctors see patients in the summer with general flulike symptoms but no sore throat or runny nose — especially in areas where ticks are common — they should presume the patient has a tick-borne disease and prescribe doxycycline, Dr. Aucott said.

Fortunately, most people treated for Lyme disease end up like Ms. Smith: The antibiotic helps quell the infection, and there are no long-lasting effects, though it may take several weeks for people to recover fully.

However, in approximately 10 to 20 percent of cases — like Ms. Shah's — a condition known as chronic Lyme (or post-treatment Lyme disease syndrome) can occur. The symptoms of chronic Lyme often include chronic pain, fatigue and brain fog.

Doctors don't know what causes chronic Lyme, and there is no diagnostic test or approved treatment for it. As a result, it has long been controversial, but the condition is gaining acceptance as research into it — and other post-infection chronic illnesses, like long Covid — grows.

"I'm hopeful that people are getting out of their mind that it's just psychosomatic," Dr. Aucott said.

Rocky Mountain spotted fever

Despite the blacklegged tick's gradual shift south, Lyme disease is still relatively uncommon in the southern half of the United States. But other tick species can cause their own problems.





In spring 2020, Elizabeth Bonitz, 52, was bitten by at least six ticks in 10 weeks. She became so ill that she told her husband she felt as if she were dying. She was eventually diagnosed with Rocky Mountain spotted fever — the deadliest tick-borne disease. Kate Medley for The New York Times

In the spring of 2020, Elizabeth Bonitz, who lives in Pittsboro, N.C., decided to start gardening with her two children to keep them occupied during the early days of the pandemic. Over a period of 10 weeks, she was bitten by at least six ticks.

Shortly before Memorial Day, Ms. Bonitz, who is now 52, started feeling sick, but “there wasn’t really anything that I could point to and say, like, ‘My stomach hurts,’ or ‘My head hurts,’ or ‘I have a fever,’” she said, adding that it was more a general feeling of malaise.

She brought the six ticks, which she had taped to a notecard, to her doctor and asked for doxycycline. But her doctor was skeptical, writing in the visit report that anxiety was probably her “main underlying issue.”

He ordered a Lyme test “to provide reassurance” per her request, and it came back negative.

Meanwhile, Ms. Bonitz continued to feel worse, so she went back to her doctor, this time requesting a full infectious disease panel. The doctor acquiesced, but said he wouldn’t write any prescriptions until he received the results.

By that point, Ms. Bonitz was in agony. She felt so dizzy and weak, it was a struggle to even walk across a room, and she had lost 10 pounds in a matter of weeks from a lack of appetite. “I said to my husband, ‘I’m dying.’”

Her husband wanted to take her to the emergency room, but in a last-ditch effort, she called a certified nurse midwife who had been acting as her gynecologist and asked for help. Upon hearing about the tick bites, the midwife prescribed doxycycline immediately.

Four days later, Ms. Bonitz’s blood test came back positive for antibodies to Rocky Mountain spotted fever. Even after she was treated, she experienced fatigue, dizzy spells and problems with her blood pressure and heart rate for a year.

Rocky Mountain spotted fever is the deadliest tick-borne disease. If left untreated, it will kill roughly 20 percent of those who contract it, said Dr. David Walker, a professor of pathology at the University of Texas Medical Branch. Even when treated with doxycycline, it is fatal in about 4 percent of cases, he said.

Early symptoms often include headache, muscle aches, malaise, fever and a rash consisting of small pink spots on the arms and legs that eventually spread to the trunk, though a rash doesn’t appear in about 10 percent of cases. As the disease progresses, the bacteria can infect the blood vessel linings of the brain, lungs and other internal organs, leading to death in as few as eight days after symptoms begin.

The disease is spread by three tick species: the American dog tick, the brown dog tick and the Rocky Mountain wood tick. Despite the name, most cases of Rocky Mountain spotted fever are detected in the Midwest and mid-Atlantic.

As with Lyme disease, Rocky Mountain spotted fever is diagnosed with an antibody test, but the antibodies typically don’t appear until seven days after symptoms start. Because of the severity and rapid progression of the disease, the C.D.C. recommends that doctors who suspect the condition should treat it with doxycycline right away, even without a firm diagnosis.

“You’ve got to treat them before day five if you don’t want death to start occurring,” Dr. Walker said.

“It’s not an easy diagnosis to make,” he added.

Alpha-gal syndrome

Another tick species, called the lone star tick, is common in much of the Southeastern and Midwestern United States, though in recent years it has traveled farther north. It is responsible for perhaps the most unusual tick-borne condition: an allergy to red meat.



When Tom Termer attended an annual meeting for the Florida Forestry Association in 2022, he went out for a steak dinner. He felt fine when he went to bed, but around 2 a.m., he woke up to find his entire body covered in hives. Lawren Simmons for The New York Times

Tom Termer, 64, has worked in the forest industry for 41 years. Throughout that time, he estimates he has been bitten by ticks “plus or minus a thousand” times.

“It’s just part of the business,” he said. “You get bit by ticks, and you pull them off and you move on.”

He doesn’t remember exactly when his symptoms started, but for several years, Mr. Termer — who lives outside of Jacksonville, Fla. — would break out in hives during the evenings. He could not connect the rash to anything consistent, so he chalked it up to job stress and didn’t worry about it too much.

That changed in August 2022, when he was attending an annual meeting for the Florida Forestry Association and went out for a steak dinner. He said he felt fine when he went to bed, but around 2 a.m., he woke up to find his entire body covered in hives. “I was in tremendous pain; there was swelling,” he said. “I’m like, What in the world is going on here?”

At a breakfast meeting the next morning, Mr. Termer sat with a business associate who started telling him about an allergy she had developed to red meat, called alpha-gal syndrome, which was caused by a tick bite.

“I’m like, Oh my gosh,” Mr. Termer said. “She’s telling me what I have.”

When Mr. Termer got home, a blood test confirmed he produced antibodies to alpha-gal.

Alpha-gal is a sugar molecule produced by all mammals except humans and other great apes. Scientists think that some species of tick, especially the lone star tick, secrete a similar sugar molecule in their saliva.

After a tick bite, human bodies “see alpha-gal as foreign, and we create an immune response,” said Dr. Scott Commins, an associate professor of medicine at the University of North Carolina at Chapel Hill School of Medicine, who helped discover the allergy in 2008.

That immune response prompts the body to produce antibodies to alpha-gal. When the newly allergic person eats red meat, like steak or pork, the alpha-gal naturally present in the meat sets off a reaction. Common symptoms include hives and gastrointestinal distress (nausea, vomiting, diarrhea); in more severe cases, low blood pressure and anaphylactic shock can occur.

Unlike with most food allergies, a reaction to alpha-gal doesn't emerge until hours after you've eaten, “which makes it really tricky to diagnose,” Dr. Commins said. “You have a hamburger at 8 p.m., you may not have hives until midnight.”

There are no treatments for alpha-gal syndrome, only strategies for managing its symptoms, namely avoiding mammal products. That includes certain foods, as well as medications and personal care products, like lotions and cosmetics, that are made with gelatin, lanolin or lactose (some people with alpha-gal are also sensitive to dairy).

When Mr. Termer received his diagnosis, he stopped eating all red meat, a dramatic change for the hunter, who is a self-proclaimed “red meat guy.”

“It's only fins and feathers now,” Mr. Termer said.

What hasn't changed for Mr. Termer is the amount of time he spends outside. “I'm an avid outdoorsman and I'm not going to stop that,” he said. But “I'm going to be more aware of ticks and tick bites and try to avoid as much of that as I can.”

Dana G. Smith is a reporter for the Well section, where she has written about everything from psychedelic therapy to exercise trends to Covid-19. More about Dana G. Smith