

When Lyme Disease Lasts and Lasts

By Jane E. Brody

Chronic Lyme disease is a highly controversial catch-all term for a host of long-lasting symptoms that may or may not stem from prior infection with the bacterium that causes acute Lyme disease. Often misdiagnosed and mistreated, chronic Lyme disease leaves thousands of people physically and mentally debilitated and without a medically established recourse.



Mary Rasenberger, 51, a New York lawyer, experienced “a series of ailments going back 10 years.” She was finally given a diagnosis of chronic Lyme disease last summer after having been told that she had multiple sclerosis.

Her long-term symptoms were “aching joints, headaches and indescribable fatigue” that made her miserable and unable to exercise. In the last few years, two additional symptoms

developed: neuropathy in her limbs and face, and vision problems. In an interview, she said she “woke up every day feeling sick”; if she became overheated, she felt as if she had the flu.

Yet a test for Lyme disease came back negative. Desperate, she finally consulted a Lyme “specialist,” one of a number of doctors who treat patients with symptoms like Ms. Rasenberger’s with long-term antibiotics, despite the fact that such a regimen has shown no significant or lasting benefit in controlled clinical trials. These trials involved randomly assigning patients to the antibiotic Rocephin (often administered intravenously) or a placebo, with neither patients nor those evaluating their symptoms aware of who got what.

Still, after several months on antibiotics Ms. Rasenberger, like many similar patients, said she felt “completely healthy for the first time in years.” Each time she tries to stop the medication, her debilitating symptoms return.

Reports like Ms. Rasenberger’s are hardly unusual, and experts now realize that some people who get Lyme disease go on to develop a chronic illness even if their initial infection was promptly diagnosed and correctly treated. Approximately 10 percent to 15 percent of people who are treated for medically documented Lyme disease develop persistent or recurrent symptoms of fatigue, musculoskeletal pain and cognitive complaints.

The condition is known as post-treatment Lyme disease syndrome, or PTLDS. “It is a real disorder, although nobody really knows what’s happening,” Dr. John N. Aucott, an

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infectious disease specialist in Lutherville, Md., said in an interview.

“A lot of patients have been told they’re not really sick, just tired or depressed,” he added. “But this is not normal fatigue, and it’s not caused by depression” — although depression certainly can result from the patient’s seriously diminished quality of life.

Antibiotic therapy for PTLDS is based on disputed reports that these patients may harbor hidden reservoirs of the spirochete causing Lyme disease, *Borrelia burgdorferi*, long after their initial treatment. But researchers who have studied the therapy have found it of little or no benefit, and many say the regimen is fraught with hazards that could be even worse than the illness.

Risks include the development of an antibiotic-resistant infection, intractable diarrhea, kidney or liver damage and, as happened to a 30-year-old woman treated with an antibiotic through a catheter, death from a systemic infection called sepsis.

People with PTLDS are not hypochondriacs seeking attention or sluggards wanting to avoid work or chores, Dr. Aucott said, though they may benefit from psychotherapy that helps them cope better with their symptoms.

“These are high-functioning people — couch potatoes don’t get Lyme disease,” he said. “They are not crazy, and the doctors who treat them are not evil. These are desperate people trying to get better, and well-intentioned doctors who are trying to help them.”

But until the causes of PTLDS are discerned, it will be difficult for researchers to find effective therapies. Among the possible causes of the syndrome are prolonged post-infection fatigue and an autoimmune reaction to the infecting organism, according to a recent book by Dr. Adriana Marques of the National Institute of Allergy and Infectious Diseases.

As for why some people with PTLDS seem to benefit from intensive antibiotic therapy, at least temporarily, Dr. Aucott suggested a few theories. The antibiotics may have an anti-inflammatory effect that relieves pain and swelling. Alternatively, patients may have a low-level, persistent infection that is temporarily suppressed by antibiotics — but not killed by them. Or it may be that some PTLDS patients experience a placebo effect, improving because they believe the treatment will help and because someone is finally taking their symptoms seriously.

Complicating the picture is the fact that some people with PTLDS symptoms apparently never had Lyme disease in the first place, Dr. Marques said in an interview. There are other infectious organisms — Epstein-Barr virus, for example — that can produce similar symptoms and may be the real culprits.

But experts cannot rule out Lyme spirochete as a cause, either. Many, if not most, people who are infected with it never know they have been bitten by the tiny deer tick that spreads the bacterium from animals to people. They may never develop or notice the red rash that can result. Even when a rash occurs, only one in five is the characteristic bull’s-eye associated with Lyme disease. Most are solid red and round or oval.

Such people may never receive treatment for the infection in its early stages and end up weeks, months, even years later with the kinds of symptoms that have plagued Ms.

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Rasenberger. Symptoms may develop gradually, as they did in my dog, which had minimal effects from a Lyme-carrying tick until nine months later, when he collapsed, unable to eat or drink on his own.

Both Dr. Aucott and Dr. Marques said more research is desperately needed if people are to get the help they need. “This is a huge disease that’s only going to get bigger, yet it receives only a tiny fraction of the N.I.H. budget,” Dr. Aucott said, referring to the National Institutes of Health.

Given the uncertainties about chronic Lyme disease, prevention is more important than ever. Avoid walking through brush and high grass. When hiking in the woods, camping, gardening or mowing the lawn, wear long, light-colored clothing and tuck pant legs into tightfitting socks. Spray exposed skin with a 20-percent DEET insect repellent and clothing with permethrin. Remove clothes before coming back indoors, and wash and dry them separately.

Shower as soon as possible after being outdoors, using a washcloth or loofah, and check your body carefully, especially in skin folds, for attached ticks. They should be carefully removed with a tweezer without crushing them by pulling gently and steadily near the mouth. Then apply an antiseptic to the site.