

# There is no Magic Cure for Post Treatment Lyme Disease Syndrome, But Many Patients do Recover with Time

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After having had effective antibiotic treatment for Lyme disease, some people continue to have problems that can last a long time. I caught Lyme disease in 1998, had a delay in diagnosis and in getting effective treatment, and so was ill for several years. I could still do many normal everyday things despite feelings of extreme fatigue which led me to spending most of each day lying down. I read a lot in those years and noticed in the literature the various descriptions of the fatigue following Lyme disease as profound, notable, unusual, debilitating, and extreme. That fit with what I experienced, and so it was clear to me that I was not the only one with the problem. It was a real shock when, after suffering for a few months, a colleague told me that it may last another three years or more. Later I asked a specialist if I could expect to get completely better, and he said that he knew patients who, after three years, had completely forgotten their fatigue, so I then thought I just had to hang on for a couple more years. There were several times in those years when I looked back and thought that the fatigue that I had felt at the same time in the previous year had been worse. That was encouraging because I realized I was slowly improving. I had been told that if I was getting better, however slowly, this was a sign that I did not need any more antibiotics, and so I did not worry that I needed any specific treatment.

I was sent by my employer to be assessed whether I was eligible for any sort of disability benefit. When I walked in the door, the doctor who was to assess me tapped his head and said "these patients with Lyme disease" as if to say that we are all bonkers. I also spoke to a supposed expert who said she told many patients every year that if they had had antibiotic treatment then their symptoms could have nothing to do with Lyme disease. At that time, there were many medical practitioners who were in complete denial that patients could have long-term problems after Lyme disease. It was the fixed ideas of those two doctors that led me to decide to explore the published literature on what has become known as Post Treatment Lyme Disease Syndrome (PTLDS). I knew that this was a hotly debated and very controversial topic, but I had worked for over twenty years in medical statistics, so it was a familiar enterprise. I collected all the relevant medical publications and pooled the data to produce a complete summary of the information in what is known as a meta-analysis, and the paper was later published [1]. Back then I was working from the starting point of knowing that the disorder is real and not all just in the mind and of knowing what the symptoms felt like.

Recently some people have tried to spread the idea that PTLDS is "just a misdiagnosis of chronic fatigue syndrome" in an attempt to minimize or perhaps deny the disorder, so I decided to write a new article on supporting patients with long term problems after Lyme disease [2], it provides important detailed information based on published findings and as I have indicated: in the article, although there is some symptom overlap, there are clear differences between PTLDS and chronic fatigue syndrome. The article has been written using my personal experience and from a search of the new published literature with the

aim of helping sufferers to be less anxious and less likely to look for some treatment that may turn out to be inappropriate.

The Centers for Disease Control and Prevention estimates that approximately 300,000 people may get Lyme disease each year in the United States. If Lyme disease is diagnosed and treated early, then the patients often have no further problems, but a small proportion of cases have a relevant delay in treatment, which may increase their risk for the development of long-term problems. These delays can sometimes result from the difficulty of diagnosis, particularly as many Lyme disease cases do not have the erythema migrans rash [3]. In their extensive review of Lyme disease, Bamm and colleagues have explored Lyme disease virulence from the perspective of host genetic and environmental predispositions. They have written about several host factors that could play a role in making some patients more susceptible to Lyme disease than others and predispose them to different disease progression. They write that studies suggest that susceptibility to the disease has an immunological component [4]. I have the autoimmune disorder Hashimoto's disease. It is easily treated with thyroxine medication, but I seem to have a genetic predisposition. In their study on a possible immunologic risk factor for PTLDS, Aucott and colleagues have written that approximately 10% to 20% of patients optimally treated for early Lyme disease develop persistent symptoms of PTLDS [5]. This suggests that many thousands of people are living with problems after Lyme disease. PTLDS is a disorder that is now recognized by the US Centers for Disease Control and Prevention, the UK Royal College of General Practitioners, and many physicians and public health faculty, and there have been studies published on it [6]. Nevertheless, there are still some physicians who have their fixed opinions and do not "believe" in the problem and who are ready to dismiss PTLDS as a mental health issue. This can lead to patients experiencing uncertainty and illness invalidation [7], and so it is no surprise that many of them then look elsewhere for understanding and support. Many countries now have Lyme disease support groups organized by patients. PTLDS can significantly impact the patient's quality of life, and it can last a long time, perhaps a few years. The fatigue can be extreme, but some people may dismiss the PTLDS fatigue as exaggerated or unimportant, perhaps because it is difficult or impossible to imagine the fatigue felt by someone else. However, once people understand the possible cause, they may be more ready to recognize it.

My article on supporting patients with long term problems after Lyme disease compiles into one summary information about what studies have found about the cause and the possible treatments. Sometimes, after eradication of the actively dividing Lyme disease spirochete, there may be debris remaining which can explain some of the long-term symptoms [2]. The expression chronic Lyme disease may be misunderstood, and some people may mistakenly think they have ongoing spirochetal infection requiring extensive antibiotic treatment, while their symptoms may be from the debris of morphological forms of Lyme disease bacteria that are resistant to antibacterial therapy, and those patients may be endangering their health by taking prolonged courses of antibiotics that can lead to other infections. In a study of autopsy tissues from a patient who had died after many years of antibiotic treatment, Sapi and colleagues found evidence of Lyme disease antigens and DNA in biofilms, and they said that one hypothesis for their persistence is that the different morphological forms may protect the bacteria from antibacterial therapy [8]. A biofilm is a thin but robust layer of mucilage adhering to a solid surface and containing a community of bacteria and other microorganisms. This multi cellular community is held together by a self-produced extracellular matrix. The mechanisms that different

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bacteria employ to form biofilms vary, frequently depending on environmental conditions and specific strain attributes [9]. The Lyme disease bacteria *Borrelia burgdorferi* is not a new organism, but recent research has suggested that the present strain of American *Borrelia burgdorferi* has a distinct clonal lineage, is more virulent and has greater inflammatory potential [10], although similar long-term problems after Lyme disease are seen in Europe. There is evidence of inflammation with PTLDS [11], and it is thought that the Lyme disease organism in biofilm form might trigger chronic inflammation [8]. Antibiotics can have anti-inflammatory effects in addition to their antimicrobial activity, and some people with PTLDS may experience a small beneficial effect from retreatment with doxycycline or ceftriaxone. Unfortunately, such retreatment carries risks, while at the same time, the Lyme disease bacteria in the biofilm may remain unaffected, and it has been speculated that the biofilm may even increase in size upon antibiotic exposure [8].

There is no known treatment for PTLDS, but some specialists have said that if the patient is getting better, however slowly, then this is a sign that no further antibiotic treatment is needed. In many patients with persistent symptoms, the symptoms fade away very slowly over time, and so it appears that there is some gradual recovery taking place, which may be neurological recovery, eventual breakdown of the debris, or a slow cessation of the chronic inflammation. There are various food supplements mentioned in my article that may help to some extent to reduce the inflammation, and there are foods that are anti-inflammatory, while other foods can be avoided because they are pro-inflammatory. However, recovery can take a long time and acceptance and patience will be necessary. Even though many patients do recover with time, there are some patients who continue to have problems, and there is variability between patients in the course of the disease. In a long-term follow up study of patients many years after their infection, Weizner and colleagues found that, of the patients identified as having possible PTLDS, a few still had PTLDS documented at their last study visit, but of those few, none were considered then to be functionally impaired by the symptoms [12].

There is increasing understanding of Lyme disease and why long-term problems can occur. It is a complicated disease, and so wide-ranging thinking and careful research are needed. As mentioned above, Bamm and colleagues have published an extensive collection of information on a range of complex topics in connection with Lyme disease [4]. They wrote that generating a more holistic understanding of the pathogens and their interface with the human host through multidisciplinary investigations is anticipated to yield data that can improve both diagnostic and treatment specificity.

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