5 myths about Lyme Disease Treatment

If you believe these myths, then you may not be comfortable with our scientific approach.

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If you believe these myths, then you may not be comfortable with our approach.

And it is VERY important that you are confident in our approach. There’s a lot of misinformation about the disease. Many supposed “facts” are really assumptions that prevent patients from seeking proper, medical help.

Lyme disease is one of the most misunderstood and misinterpreted diseases in the world today. This is a strange fact since some estimates of occurrences place it at about 200,000 cases that in turn place it at epidemic proportions. As it stands, confirmed cases have been steadily rising over the past decade, making it a far worse problem than the media babies of the swine flu and West Nile, among other things. Why is it so out of focus in the media and for medical practitioners?

There are reasons for the marginalization of Lyme disease that are easily remedied with a little education and a little brainpower. Below are some myths we need to debunk.

Our purpose in debunking these myths is to present a medical viewpoint and ask you to reconsider your “thinking” about Lyme disease, and get proper medical treatment. If the Haverford Wellness Center is not a viable solution for you then we encourage you to be vigilant in finding an appropriate Lyme literate physician.

You will see that in most cases there is a “little” bit of truth to every myth. The problem arises when it’s applied to all Lyme disease cases. We will do our best to make this helpful, and not overly technical. If you have additional questions you can always give us a call at 215-256-0050.
I didn’t get a “rash” so I don’t have Lyme disease

It’s true that about 60%-80% of Lyme patients report skin rash that has a “bull’s eye” appearance. It begins as a reddened area near the tick bite. As the rash increases in size, it clears in the middle and develops a red ring around the outside.

This rash:

- May expand to a very large size.
- Is usually not painful or itchy.
- Often appears on the thighs, groin, trunk and armpit.

And if it’s the classic bulls-eye rash, then it’s a very strong sign that you probably have Lyme disease.

But what about the 20%- 40% who didn’t get a rash, or didn’t see or recognize the rash? The early signs and symptoms of Lyme disease (fever, chills, headache, muscle/joint pain and fatigue) are similar to other ailments. They can still have Lyme disease, however, they don’t know it.

In addition you may see “multiple rashes” such as those shown in the photo. The rash is not caused from multiple tick bites, but occurs as a reaction when the bacteria moves through the body.

The truth: you can have Lyme without the “rash”. And confirming a Lyme diagnosis can be difficult, especially if you and/or your doctor don’t consider it as a possibility.
Lyme Disease is Easily Diagnosed

The IDSA guidelines approach Lyme rather simplistically.

In those guidelines all you need is a blood test and a rash to diagnose along with other clinical symptoms. After that, "Treatment usually involves 10-28 days of oral antibiotics and is highly effective. When Lyme disease is diagnosed and treated quickly, 95 percent of people are cured within a few weeks of treatment."

That may be true if you have the rash, if you get medical treatment quickly, and if there are no other “bacteria” introduced into the body.

Lyme is a very evasive bacteria and, unlike other bacteria, getting an “accurate positive” test is complicated, even controversial. There are various tests for various stages, the laboratory work has to be very precise, and there are many roads that lead to false conclusions. Throw in other infections that affect the test results and you get a picture of the challenges we both face.

We know as a patient this is frustrating. There’s an “accurate positive” test for the HIV virus and for so many other bacteria. Why not Lyme? The answer is long and complicated, so we’ll just try and give you a layman’s understanding, and explain our process for an accurate diagnosis of Lyme disease.

Lyme disease Symptoms vs. the Lyme bacteria – A big difference
For most patients, diagnosis of Lyme disease remains clinically based, that is, a diagnosis based primarily on symptoms of Lyme disease alone because, unfortunately, there is no test available that is 100 percent accurate to rule out or confirm the infection. False positive results and false negative results are common. However, for us, symptoms of Lyme disease alone are not enough. At the Haverford Wellness Center we go the extra mile to make sure the infection is present before we start treatment, but "testing is a big problem.

Common Testing problems and false results
The most common and current tests available today are limited to determining if antibodies to the Bb organism exist. The body creates antibodies after being exposed to the Bb organism. Lyme antibodies can remain in a person's body long after the Lyme organism has been eliminated. This means that a positive Lyme antibody test does not accurately indicate if active Lyme bacteria continue to be present in the body.

The ELISA and Western Blot tests are the most common tests currently used to confirm the presence of Bb antibodies. The first step calls for a test such as the ELISA to be conducted. If positive, a Western Blot test is done in hopes of confirming that Lyme antibodies exist. However, even if Lyme antibodies exist, it does not mean that the patient has Lyme disease.
Further complicating matters is the fact that antibody tests can confuse Lyme antibodies with antibodies created by other complications in the body, including antibodies created in reaction to bacteria other than the Bb organism. This means that these two tests are not completely accurate. It also means that it is common to receive false positive and false negative results when using the ELISA or Western Blot tests. In other words, a negative test result cannot guarantee that Lyme antibodies do not exist. Conversely, a positive test result cannot guarantee that you actually have Lyme antibodies in your system. In both cases, accurate positive antibody test results do not mean that you even have active Lyme bacteria in your system.

**The PCR Test – the gold standard for Lyme disease**
Not as well known but very effective is the PCR test. The Polymerase Chain Reaction (PCR) test confirms that Lyme bacteria are present in the body. The PCR test is relatively new. It is designed to confirm that Lyme bacteria DNA are present. A positive PCR test almost always guarantees that you have Lyme disease, depending upon the accuracy of the lab that performed the work. A negative PCR doesn’t prove you don’t have Lyme. However, we have PCR strategies that can help you confirm this. The second note on testing has to do with the fact that test results often vary depending upon which lab performs the test. Both of the labs we use specialize in Lyme testing.

**C6- Peptide Test – the newest entry**
The Lyme C6 Peptide ELISA is very different than the earlier Lyme ELISA test. It was developed at Tulane University and available since 2000. It can confirm exposure in more that 60% of patients. The chance of a false positive result is under 1%. While this new test, when positive, can confirm that an individual is infected with Lyme disease, there is still no test clinically available that, when negative, proves that an individual does NOT have Lyme disease. The hunt for better tests goes on.

**Co-infections – more confusion**
Testing for Babesia, Anaplasma, Ehrlichia and Bartonella (other tick-transmitted organisms) should be performed. The presence of co-infection with these organisms points to probable infection with the Lyme spirochete as well. If these co-infections are left untreated, their continued presence increases morbidity and prevents successful treatment of Lyme disease. (More on that later.)

Just reading the above can be confusing. We probably overkilled on all the different tests, but if you haven’t even heard of any of these tests, then we want them to be part of your new Lyme vocabulary. So here’s the bottom line. We believe it is possible to accurately diagnose Lyme. We’ve done it. However, the truth is, it is not easy.
Myth 3

Lyme Disease is easily cured

Again, there is some truth in this. If you detect the bull's-eye rash, and you get oral antibiotic treatment in 3-28 days, in 95% of the cases you can be cured. But what if you have all the symptoms of Lyme disease and never remember a tick or a rash?

If you read information about Lyme disease on the Center for Disease Control website you will find them very simplified (although at the time of this writing they are being reviewed).

The CDC offers an even simpler course of treatment than the IDSA, further ignoring clear complications that persist in both diagnosis and treatment. The idea that Lyme disease can move from an acute illness to a persistent and chronic illness is at the center of a political battle. The IDSA insists there is no such thing as "chronic" Lyme disease and insists that persistent symptoms must be due to some other problem, often psychosomatic. In other words, since there is no such thing as chronic Lyme disease, a patient insistent on persistent symptoms must have a mental problem. The IDSA states, further, as the IDSA argues, "In more than 20 years there has not been one scientifically valid study published in the peer-reviewed medical literature that proves that the benefits of long-term antibiotic treatment outweighs the risk." Yet, according to many, we must question what they mean by "not one scientifically valid study." Ignoring other studies and not confirming them at all does not mean that one's assertions are therefore factual.

Some people believe the IDSA has its own agenda to protect the credibility of the Lyme tests in use today. Who knows? We can only relate our experiences.

Based on our own experience, and methodical Lyme research, we have a wealth of knowledge that allows us to accurately diagnose and cure Lyme disease. In addition, after treatment, 86% of our patients no longer have the Lyme bacteria in their body. The following cure information is based on our experience, and it can be complicated.

Proper treatment of Lyme disease is based on an “accurate Lyme diagnosis”
Each Lyme patient is different. Each bacteria is different. Each treatment of Lyme disease is different. One of the reasons our evaluation is so thorough, and the diagnosis is so important is, the better the information about the disease, the higher chance of the right treatment of Lyme disease the first time. This is a critical step in reaching the cure.

We will most likely use antibiotics
Lyme disease is a bacterial infection and like other bacterial infections it is treated with antibiotics. Antibiotics are administered orally, with intramuscular (IM) injections, or intravenously (IV) through the veins. Physicians often prescribe combinations of antibiotics to take advantage of the diverse ways that individual antibiotics affect the Bb organism.

We realize there are downsides to antibiotics. However, in our experience, when fighting Lyme the advantages far outweigh the disadvantages. Also, we have Lyme detoxification treatments that can assist you back to health.

**Effective antibiotic treatments are longer than most and often intravenous**

Some health care professionals are more conservative in their approach to Lyme disease and often don't go much beyond relatively short-term oral antibiotic therapy. This group believes that in almost all cases, one or two courses of oral antibiotics are all that are required to eradicate the bacteria. They believe that persistent, chronic Lyme disease symptoms are not the result of an ongoing infection of active Lyme bacteria in the body but rather, are probably the result of a dysfunctional autoimmune system response or some other process occurring in the body.

Peer reviewed medical literature describing late stage Lyme disease consistently show the involvement of the central nervous system. And the only antibiotics that cross the “blood-brain” barrier, and have the hope of eradicating the Lyme disease bacteria can ONLY be administered intravenously. That has been our experience.

**Feeling worse before feeling better**

Sometimes a reaction to antibiotics occurs when symptoms recur, flare up, or become exaggerated. Some call it a healing crisis, while others describe it as getting worse before you get better. Lyme patients refer to this reaction as a "herx," or say that they are "herxing."

It usually occurs within days to weeks of starting antibiotic therapy. When antibiotics directly kill Lyme bacteria or work with the body's immune system to kill the organism, toxins are released that cause either "direct reactions" or indirect actions through stimulation of the immune system. In simpler terms, the reaction occurs when Lyme
bacteria are killed off more quickly than the body's organs (kidneys and liver) are able to process them. This increases the number of toxins in the bloodstream. The higher the toxin count, the more severe the symptoms the patient experiences.

The bottom line is, sometimes the cure is easy. Often it is not, especially if not treated very early. However, in our experience, in 86% of the cases we’ve treated, it IS curable.

**Myth 4**

**Chronic Lyme disease is all “in your head”**

Lyme disease can be “the great pretender” and share common symptoms with many other diseases. So indeed, Chronic Lyme disease may be used by some as a catch all for many other diseases.

Symptoms persist and worsen in enough patients that we must question the validity of this myth. Using a psychosomatic diagnosis as a baseline to describe these instances is plainly irresponsible. There is clearly more evidence of persistent, chronic Lyme than required to question the validity of defaulting to the "it must be something else" dogma. If it is both more difficult to detect than we once believed and more difficult to treat and cure than we once believed, it is only reasonable to assume that the clinical evidence presented to date raises significant doubt that the IDSA has got it right. If they are looking for "scientifically valid" in terms of lab cultures and serology, it is reasonable to assume that this cannot account for the whole picture based on the clear evidence that Lyme is very difficult to detect.

The truth: There are probably some people who are misdiagnosed as Lyme patients who don't have the bacteria. But, from the years of suffering we have seen in our patients and our own experience in successfully treating, it proves to us that chronic Lyme disease does exist, can be treated, and is definitely not "in your head."
**Myth 5**

**Once the Bacteria that Causes Lyme is Killed Off, You are Cured!**

Yes, you’re cured from Lyme disease, but you may still need to be cured of other infections.

Research is uncovering more and more that the bacteria that causes Lyme disease has a lot of bacteria “friends”. This is part of the reason why diagnosis and treatment are difficult. Even if all of the Lyme bacteria are out of one's system, there is no guarantee that all infections as a result of the treatment are cured as well.

Symptoms and treatment of Lyme co-infections are as complex as Lyme itself. Similar to the Lyme symptoms, these Lyme co-infections are also non-specific, such as fever, chills, headache and malaise. The diagnostic procedures often rely on a series of negative tests, since the parasites and bacteria that cause the infections are only detectable in the bloodstream for a short period of time. This is why it is so critical for patients to have a co-infection workup completed at the time of their initial diagnosis, when the likelihood of an accurate diagnosis is at its highest.

The National Institutes of Health also recognizes the dangers associated with Lyme disease co-infection, noting that co-infections have the potential to make Lyme diagnosis more difficult and to weaken patients' immune systems, compromising their ability to fight off the initial Lyme infection. In fact, a landmark study of Lyme co-infections found that patients who were diagnosed with both Lyme disease and Babesiosis had an average of three more symptoms and an average disease duration that was two weeks longer than those who were diagnosed with Lyme disease alone. Researchers found similar complications among patients who were infected with Lyme disease and Erlichiosis.

We encourage patients to be aware of the following information and symptoms for these three most common tick-borne co-infections, and to discuss testing and treatment protocols with their physicians:

**Babesiosis** is an infection caused by a parasite that infects red blood cells. Babesia microti is believed to be the most common piroplasm infecting humans, but scientists have identified over twenty piroplasms carried by ticks. Ticks may carry only Babesia or they may be infected with both Babesia and Lyme spirochetes. The first case of babesiosis was reported in Massachusetts 40 years ago, but cases have been reported all across the U.S., Europe and Asia since then.

Symptoms of babesiosis are similar to those of Lyme disease but it more often starts with a high fever and chills. As the infection progresses, patients may develop fatigue, headache, drenching sweats, muscle aches, nausea, and vomiting. Babesiosis is often so mild it is not noticed but can be life-threatening to people with no spleen, the elderly, and
people with weak immune systems. Complications include very low blood pressure, liver problems, severe anemia (a breakdown of red blood cells) and kidney failure.

**Ehrlichiosis** is common in two forms, both of which are caused by tick-borne parasites called Ehrlichia that infect different kinds of white blood cells. In HME (human monocytic ehrlichiosis), they infect monocytes. In HGE (human granulocytic ehrlichiosis, also called anaplasmosis), they infect granulocytes. Ehrlichiosis and anaplasmosis share the same symptoms: sudden high fever, fatigue, muscle aches and headache. The disease can be mild or life threatening. Severely ill patients can have low white blood cell count, low platelet count, anemia, elevated liver enzymes, kidney failure and respiratory insufficiency.

Effective diagnosis is difficult, as only two species of these parasites have been identified and scientists believe there may be dozens of other species causing Erlichiosis. Ehrlichia parasites multiply inside host cells, forming large mulberry-shaped clusters called morulae which doctors can sometimes see on blood smears, but most often a diagnosis is surmised when patients do not respond well to treatment for Lyme disease.

**Bartonellosis** is known to be caused by a bacteria carried by fleas, body lice and ticks. Scientists suspect ticks are a source of infection in some human cases of bartonellosis. People with tick bites and no known exposure to cats have acquired the disease. People who recall being bitten by ticks have been co-infected with Lyme and Bartonella. More research needs to be done to establish the role of ticks in spreading the disease. Bartonellosis is often mild but in serious cases it can affect the whole body.

Early signs are fever, fatigue, headache, poor appetite, and an unusual, streaked rash. Swollen glands are typical, especially around the head, neck and arms. Lymph nodes may be enlarged and the throat can be sore. Polymerase chain reaction (PCR) and tissue biopsy can be used to confirm a diagnosis; however they are insensitive, as are standard blood tests.

The truth: Yes, if we eliminate the Lyme bacteria, you are cured of Lyme disease. However, ticks are dirty creatures and collect a variety of bacteria. Nonetheless, if a disciplined approach is taken to find and eliminate each bacteria, a full recovery of all infections is possible.

**In summary**
These are the top 5 Myths we find patients seem to accept as truth and we hope this helps clarify things a bit for you.

There’s more information on our website including [Frequently Asked Questions](#) and a [News and resources page](#) for websites that have extensive Lyme and Lyme support information. If you want to learn more about our approach please visit us at [www.HaverfordWellness.com](http://www.HaverfordWellness.com) or call in PA 1-215-256-0050.