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LYME DISEASE PATIENT GUIDE

WHY THE NEED FOR A GUIDE?

What should seem to be straightforward, like for so many other bacterial infections, with Lyme disease it is actually not. Rarely, the medical world has been divided about a disease as it is with Lyme disease. If many people are healed by the primary care provider (PCP), or by an infectious disease doctor, many others may suffer from chronic or persisting symptoms after an episode of Lyme disease.

Is Lyme disease chronic or not? Is the standard Lyme disease blood test reliable or not? Opinions diverge. Most of the time the controversy is unknown or not well known. Whom to see? What to do? Whom to believe? If not Lyme, what is it? Unless a physician is aware of the controversy and knowledgeable enough to decide which guidelines to follow, a physician will always apply the only standard of care as established by the IDSA/CDC. Caring for Lyme disease patients, I can often hear these questions. The purpose of this guide is not to favor one opinion over the other, but to make Lyme disease patients aware that a reliable controversy exists and to answer these questions.

WHO IS THIS GUIDE FOR?

For people who have persistent symptoms after a Lyme disease treatment.

The Center for Disease Control (CDC) warns that some Lyme disease patients will present chronic lingering symptoms that may last months or years of an unclear nature. This is what the CDC calls the Post Treatment Lyme Disease Syndrome (PTLDS). The CDC writes: *"It is not uncommon for patients treated for Lyme disease with a recommended two to four week course of antibiotics; to have lingering symptoms of fatigue, pain, or joint and muscle aches at the time they finish treatment.".*

The concern of persistent and resistant symptoms for years is also recognized by the Infectious Diseases Society of America (IDSA). Dr. Gary Wormser from IDSA from the Westchester Medical Center writes: "*Late Lyme Borreliosis may develop among some untreated patients, months to a few years after tick-transmitted infection. The major manifestations of late Lyme Borreliosis include*

arthritis, late neuroborreliosis (peripheral neuropathy or encephalomyelitis). In up to 10% of patients, arthritis may persist for months or a few years despite treatment with antimicrobials." The CDC admits: "*Unfortunately, there is no proven treatment for PTLDS".*

For People Who Have a Chronic Illness Compatible with Lyme Disease, but with a Negative Lyme Disease Blood Test.

If your Lyme disease blood test is negative, despite a clinical presentation compatible with Lyme disease; and that no definitive diagnosis was made despite extensive workup and multiple medical visits. Or, that you do not accept the diagnosis that was given to you, you may want to consider other diagnostic criteria.

IDSA VS. ILADS

The controversy over Lyme disease opposes the Infectious Diseases Society of America (IDSA) with the International Lyme and Associated Diseases Society (ILADS). Both have different diagnostic criteria and therapeutic protocols.

IDSA is the voice of most infectious disease doctors, and is endorsed by the CDC. Therefore, it represents the standard of care. The IDSA Lyme disease guidelines followed by most of the infectious disease specialists have been established by a panel of 14 experts in 2006. For IDSA, the Lyme disease blood test is reliable and enables not only to diagnose when the blood test is positive. But, also this test rules out Lyme disease when it is negative. IDSA claims that chronic Lyme disease is a misnomer that should be called Post-Treatment Lyme Disease Syndrome (PTLDS), because it is not due to a bacterial infection.

The CDC and IDSA strongly recommend against treating with antibiotics after one month of treatment. The CDC states: "*Although short-term antibiotic treatment is a proven treatment for early Lyme disease, studies funded by the National Institutes of Health (NIH) have found that long-term outcomes are no better for patients who received additional prolonged antibiotic treatment than for patients who received placebo. Long-term antibiotic treatment for Lyme disease has been associated with serious, sometimes deadly complications*".

If ILADS is composed of physicians from different specialties who have dealt with Lyme disease for decades, ILADS is essentially the voice of a divergent medical literature which does not agree with the conclusions of IDSA and CDC. Medical knowledge comes from research and is archived in medical and peer reviewed journals. Medical literature is created from many different opinions.

Medical education for a very practical reason is channeled down to the primary care physician through a concise and summarized format where divergent opinions may be overlooked. For ILADS, the standard Lyme disease test is not reliable. ILADS, also, states that the Lyme bacteria can persist despite antibiotics echoing the research of Dr. Yin Zhang, Professor of Molecular Microbiology and Immunology at John Hopkins University, who demonstrated the existence of a subgroup of Lyme

bacteria, called persister cells. These cells remain in a dormant state avoiding the effects of antibiotics with the capacity to "wake-up" after antibiotics.

In 2015, Dr. Lewis of Northeastern University published a report that confirmed Johns Hopkins original findings that the bacteria that causes Lyme disease forms dormant persister cells. ILADS is also the resource of medical education to train physicians to be proficient in tick-borne diseases.

THE AMPLITUDE OF THE CONTROVERSY

The controversy is not only between doctors, but also between states. Some states like New York authorize doctors to treat Lyme disease with antibiotics for a long period of time. Some other states like New Jersey don't. Virginia state obligates laboratories to warn that the Lyme disease blood test is not reliable. The state of Georgia warns that "*the CDC's case definition used to report Lyme disease should not be used for clinical diagnosis as many patients may not meet reporting criteria yet may still be infected.*" Institutions may be divided as well. Some doctors from Columbia University follow the IDSA guidelines while some others support ILADS.

OVER OR UNDERDIAGNOSING

IDSA and CDC are concerned about over-diagnosing Lyme disease and the inappropriate use of antibiotics. Long-term use of antibiotics is a serious concern and should always be fully justified.

Under-diagnosing is also a real problem. The typical Lyme disease patients that I see, saw beforehand on average 10 to 15 physicians. The diagnosis of Lyme disease, according to the standard of care, without a positive blood test, cannot be made. Patients see multiple physicians, leaders in their field and are left without diagnosis other than psychosomatic disorder or fibromyalgia. One of my patients saw eight infectious disease doctors. None of them thought of Lyme disease. A ninth infectious disease doctor that was consulted made the diagnosis of Lyme disease. This patient, however, was already emotionally broken. She was sobbing trying to convince me that she was not psychiatric, what many other doctors tried to convince her. Many are given the diagnosis of psychiatric or psychosomatic disorders, anxiety, depression or fibromyalgia.

NEXT STEP AFTER A NEGATIVE LYME DISEASE BLOOD TEST

Do not think that you do not have Lyme disease. There is enough medical literature to support the non-reliability of Lyme disease blood testing. I recommend filling out a Lyme disease questionnaire. Having typical clinical signs and association of systems significantly increases the likelihood of Lyme disease. A typical Lyme disease patient complains of a few symptoms. An extensive questionnaire pertaining to Lyme diseases, almost all the time, finds at least ten more symptoms that the patient had no clue they were related to Lyme disease. Cognitive disorders like memory impairment, difficulty focusing, psychological disorders like new onset of depression,

anxiety, irritability, personality change, hormonal disorders, etc., are most often not claimed by the patient as symptoms of Lyme disease.

Going through a full Lyme disease questionnaire takes at least 35 minutes and may be quite challenging for 10-15 minute medical visits. I found it very useful to send a questionnaire to the patient in advance of their appointment, and to receive it with enough time to review it prior to the visit. In my practice, I ask for the completed form three days before their appointment.

I have still to spend one hour and a half to characterize a Lyme disease pattern and untangle all associated factors. The absence of any explanation despite an extensive workup conducted by expert physicians, along with a positive questionnaire is the best clue for Lyme disease. All other possible medical conditions that are compatible with the clinical manifestations should always be first ruled out. The Lyme disease test can be repeated in different ways and in different laboratories more accurately than others. Some will decide to have an empirical treatment based on clinical presentation and absence of any other diagnosis.

NEXT STEP AFTER A POSITIVE LYME DISEASE BLOOD TEST

Having a positive Lyme disease blood test does not always mean that Lyme disease is active or current. Lyme disease can be isolated or associated with other factors that may aggravate or impede the treatment.

Is Lyme disease current or past history?

A positive serological Lyme disease test only testifies of an immune response to the exposure of the Lyme bacteria that may have happened in the past. It does not mean you are suffering, today, from Lyme disease. The same way measles, mumps or rubella titers only testify of past exposure to the virus either from vaccine or disease and will remain forever positive. Lyme disease titers only testify of an immune reaction and may remain positive for years. Other diseases, infections, and tumors may coexist with a positive Lyme disease blood test. This is why it is important to exclude all other medical conditions and why, here too, a full screening questionnaire is necessary. Like for any other testing in Medicine, there must be a clinical correlation to validate the test result as plausible.

If no past history, what could imitate Lyme disease? Or, what could be associated with Lyme disease?

Some medical conditions can look very much like Lyme disease. For example mold toxicity, heavy metal toxicity, environmental illnesses, porphyria, multiple chemical sensitivity, electro-magnetic frequency hypersensitivity, PANDAS and PANS, mast cell activation disorder, limbic system dysfunction etc. We arrive at the paradox where about 50% of individuals who truly suffer from Lyme disease have a false negative serological blood test for Lyme disease. While some others have positive Lyme disease test, but remain without symptoms or suffer from other conditions in combination or not with Lyme disease. We may see, for example, people with a positive Lyme

disease blood test due to a tick bite that happened many years ago, who are really suffering from mold exposure.

The range of clinical manifestations and of severity between Lyme disease patients are too vast to be caused only by one bacteria. Most of the time, chronic or resistant symptoms after the initial treatment of Lyme disease are due to associated pre-existing or co-existing factors. Most often what we see is a combination of different problems that aggravate or activate each other. Mold exposure can be silent, asymptomatic until the patient gets bitten by a tick and vice versa. Any other co-infection either transmitted by the same tick or pre-existing, such as mononucleosis, CMV, HHV-6, mycoplasma etc., any other source of inflammation (including inflammatory diet), any hormonal or metabolic imbalance, any immune deficiency state or nutritional deficiency may contribute by large to the severity of the illness. Addressing and treating all aggravating cofactors of Lyme disease, not only enable the antibiotics to work but also to be less necessary.

Preparing the Patient to Avoid a Herxheimer Reaction

The next logical step after a positive Lyme disease blood test should be to receive an antibiotic treatment. Giving antibiotics to a Lyme disease patient, however, runs the risk of triggering a Herxheimer reaction which is specific to Lyme disease.

The Herxheimer reaction is believed to occur when injured or dead bacteria release their toxins into the blood and tissues faster than the body can comfortably handle it. When you start to herx, the body's tactics for removing the toxins are overburdened due to an accumulation of toxins. To the opposite of the usual side effects, that are different from the initial patient's complaints, Lyme disease patients on antibiotics may experience a worsening of their Lyme symptoms. This is why detoxification is crucial in the treatment of Lyme disease.

Treating Associating Factors that Aggravate Lyme Disease and Impede the Treatment

My first step after a positive Lyme disease blood test is to look for other contributing factors, to strengthen the health status by replenishing nutritional deficiencies and by detoxifying. By doing so, I rarely see Herxheimer reactions. It is not uncommon to see Lyme disease patients be improved by 50% only by these steps without the use of any antibiotics.

This gives the option either to reinforce the detoxification process with care of other lateral factors like mold exposure, for example, without the use of antibiotics. Herbal therapy, essential oils, are then often used. Most of the time, however, antibiotics will be started after a detoxification period.

LYME CONTROVERSY OR LYME CONFUSION?

If Lyme disease was only an infectious disease due to a bacteria, changing antibiotics or the use of multiple antibiotics, normally mastered by infectious disease doctors, should overcome Lyme disease like any other bacterial infection. The difficulty encountered in many Lyme disease patients to control

the symptoms; and to prevent their relapse, shows that Lyme disease is not only a simple infectious disease. ILADS agrees with IDSA that the chronic illness following an episode of Lyme disease is due to a state of inflammation. ILADS would, however, claim that the Lyme disease bacteria plays a role of trigger and persists despite antibiotics. Lyme disease is too often confused with tick-borne diseases. Lyme disease is due to a bacteria called *Borrelia Burgdorferi* that is transmitted by a tick bite.

The tick bite, actually, contains more than one type of bacteria but may transmit several types of bacteria, parasites, and even viruses like *Bartonella, Ehrlichia, Anaplasma, Babesia, Rickettsia,* etc., causing what we call co-infections. If each species has specific features, they, however, share many clinical signs responsible for a tick-borne disease. Reducing a tick-borne disease to *Borrelia Burgdorferi,* causes us to overlook co-infections and to be misled by a negative Lyme disease blood test; while the search for co-infections could have been positive for other tick-borne diseases. Co-infections should always be looked for along with the standard Lyme disease blood test.

IDSA PHYSICIAN OR ILADS PHYSICIAN?

IDSA physicians are best to treat infectious diseases. Lyme disease is, however, far from being due only to bacteria, but rather to the complex interrelation of multiple co-existing or pre-existing factors. Hence, the diversity of clinical manifestations and of successful treatment. Since many patients see their symptoms of Lyme disease disappear with the initial antibiotic treatment, patients may see their primary care physician or an infectious disease doctor to initiate treatment.

Patients who are concerned about Herxheimer reaction, passage to chronic illness status if insufficiently treated (contrary to the IDSA/CDC's opinion), co-infections or prefer another therapy (essential oils, herbal therapy, Disulfiram, Ozone etc...) than antibiotics may elect to see initially an ILADS physician. Taking care of resistant Lyme disease patients to treatment takes skill way beyond the infectious disease realm to identify and untangle all possible contributing factors (see above).

As a physician trained by ILADS, I, therefore, found it logical to complete my education in mold exposure and indoor health threats by joining the International Society of Environmentally Acquired Illnesses (ISEAI), mast cell activation disorder, detoxification, and PANDAS by joining the PANDAS Physician Network (PPN). I have also incorporated in my care the help of experts in genetic analysis to understand how the biochemistry of each one may contribute to illness or impede the treatment.

CONCLUSION

When patients do not get better despite diagnosis and treatment given by expert physicians… When physicians admit to not understanding, or when patients get referred from specialist to specialist without resolution…

When patients or parents refuse the diagnosis of anxiety, depression, psychosomatic or psychiatric disorder or fibromyalgia…
Patients/patient's guardians may then consider that other opinions exist.

The use of antibiotics beyond a period of one month, strongly not recommended by the CDC, has to be weighed against the chronic use, sometimes for life, of painkillers, anti-inflammatory drugs or psychiatric medications; and *the emotional burden of an ill-defined chronic disease in the absence of any satisfying diagnosis*.

Always try to discuss with your PCP all options you come across. A wealth of medical education about Lyme disease is now readily available either from ILADS at ILADS.org, netcaplyme.com, LymeNet.com or Lyme Disease.org among others to help you understand this controversy and ultimately make your own well informed choice. Visit the Resources page of my medical practice website, www.massfunctionalmd.com

Please, share your feedback with our office.

Has anyone else had a similar experience? What was missing that would have made it easier for you to seek treatment?

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