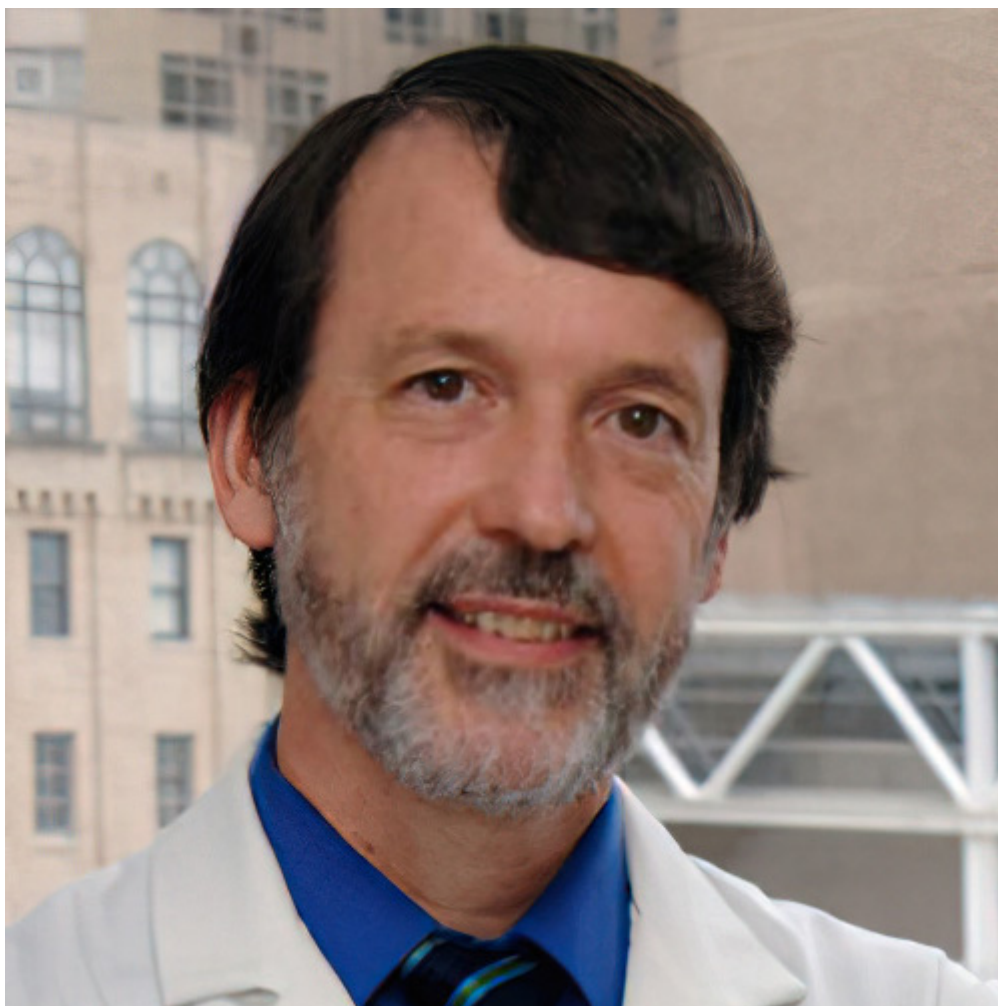


## How Might a Doctor Respond to a Patient with Relapsing Lyme Symptoms?

For far too long, patients have gotten the short end of the stick in the so-called “Lyme wars” – the deeply entrenched medical divide about the diagnosis and treatment of Lyme disease.

In *Conquering Lyme Disease: Science Bridges the Great Divide*, co-authors Brian A. Fallon, MD, and Jennifer Sotsky, MD, put forth a different idea. They say that recent scientific advances are reshaping our understanding of the illness — and closing the gap between the two factions. They say there is cause for both doctors and patients to be optimistic about the future of Lyme disease treatment.

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Brian A. Fallon, MD



### Jennifer Sotsky, MD

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In outlining the issue, however, they do not overlook the very real suffering that many patients have experienced at the hands of their medical practitioners. They assert that the politically charged climate surrounding Lyme disease can severely impact the physician-patient relationship.

Patients who remain ill after receiving standard Lyme treatment, the authors say, “may start to feel disbelieved, marginalized, or abandoned by the medical community.”

## CONQUERING LYME DISEASE:

### Science Bridges the Great Divide

**AUTHOR:** BRIAN A. FALLON, MD AND JENNIFER SOTSKY, MD

In **Conquering Lyme Disease: Science Bridges the Great Divide**, co-authors Brian A. Fallon, MD, and Jennifer Sotsky, MD, put forth a different idea. They say that recent scientific advances are reshaping our understanding of the illness—and closing the gap between the two factions. They say there is cause for both doctors and patients to be optimistic about the future of Lyme disease treatment.

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In the following excerpt, Fallon and Sotsky explore how doctors sometimes respond to their patients with relapsing symptoms.

If one is confident in the wisdom of academic experts that one course of antibiotic treatment is curative for most patients, a reasonable approach by a health care provider when faced with a patient whose symptoms have not improved would include searching for another possible illness that has not yet been considered.

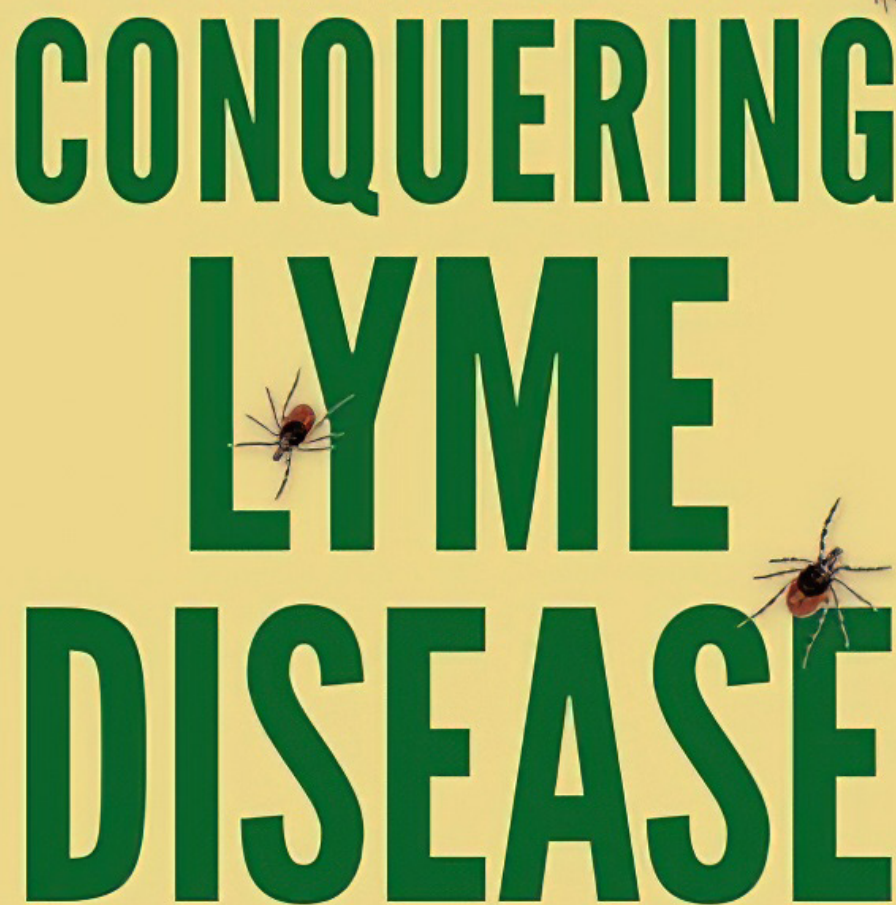
1. **The patient may be depressed or overly anxious** because there is a combination of low energy, irritability, and changes in sleep patterns.

2. **The patient may have fibromyalgia** because there is widespread pain.
3. **The patient may have chronic fatigue syndrome** because daily sleep intervals extend to twelve to fourteen hours and the patient's physical functioning has dramatically declined.

Consideration of these alternative explanations is reasonable and part of good medical practice, especially given that we now know that certain environmental triggers (such as infection) can lead to residual mood disorders, persistent fatigue, and musculoskeletal pain.

The problem is not that the physician is considering these other possibilities to enhance care of the patient; indeed, these other diagnostic considerations may provide new directions for treatment. The problem is that the physician may be completely opposed to the possibility that the patient may still have residual infection and/or that another course of antibiotic therapy might confer benefit.

The physician may take umbrage when patients bring in articles or relate anecdotes suggesting that repeated antibiotic treatment for some cases of Lyme disease may be necessary. The patient comes to feel shut out, unheard, and uncertain whom to trust. Even in instances in which the doctor's recommendations might in fact have validity, the patient who feels unheard will remain doubtful about the doctor's judgment and unlikely to follow through.



# CONQUERING LYME DISEASE

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SCIENCE BRIDGES THE GREAT DIVIDE

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**BRIAN A. FALLON, MD**  
**AND JENNIFER SOTSKY, MD**

When the patient's symptoms not only persist but become more numerous, the patient becomes alarmed and somatically preoccupied. Whereas when there is an explanation and plan of action, or even the



## How Might a Doctor Respond to a Patient with Relapsing Lyme Symptoms?

sense that the doctor has absorbed the information and is giving it thought and attention, patients are better able to relax their vigilance. When the doctor responds by blaming or brushing the patient off, the patient will feel doubly traumatized. As a result of this physician-patient interaction, the subjective experience of pain and confusion imposed by the illness becomes compounded by a kind of physician-induced post-traumatic stress disorder.

Doctors are trained to be able to give answers and find solutions. When a patient presents with a litany of symptoms that do not fit into the doctor's known paradigms or that are unsupported by laboratory evidence, that doctor may be tempted to discount those aspects of the patient story that do not fit. The doctor may not want to treat that patient, knowing that he or she does not know how to help or fearing that engagement with this patient might take him into controversial medical waters.

*Lyme disease is one of those illnesses that remind us of the value of old-school medicine: knowing the patient as a person, knowing how the current presentation fits into his or her life as a whole, and listening very carefully to the details of the clinical history.*

The current climate in health care delivery poses particular challenges for the patient with a complex or atypical disease presentation, such as those manifest in many of our patients with late-stage post-treatment Lyme disease symptoms. The traditional functions of the physician—listening carefully to the patient's history in order to create a differential diagnosis and sitting by the patient's side to offer human comfort in the face of physical and mental suffering—have been marginalized to the periphery in favor of a checklist of questions and laboratory tests.

Instead of looking at the patient and listening, the physician of today is often found staring at a computer screen, typing in answers to questions that look good for the medical record but are not necessarily focused on unraveling the individual patient's complex presentation.

This means that doctors are deprived of an invaluable source of information: the patient him- or herself. Patients and their family members have important insights to provide the physician regarding their former functioning and how the current presentation differs from their habitual selves. Lyme disease is one of those illnesses that remind us of the value of old-school medicine: knowing the patient as a person, knowing how the current presentation fits into his or her life as a whole, and listening very carefully to the details of the clinical history.

Guidelines that were developed to convey and clarify the typical presentation and course of an illness fail to address the outliers whose lab values or clinical trajectory fall outside of the norm. Could this patient be an outlier? Could this patient have Lyme disease even if the presentation and course are atypical? Even if the lab tests are equivocal? Some physicians ask themselves such questions. Others do not.

Some doctors love the complicated patient, experiencing such encounters as a challenge, an opportunity for a “Dr. House” moment—finding the thread that unravels the disease and revealing the elusive diagnosis. Other doctors may feel quite uncomfortable evaluating patients who do not fit known patterns and whose symptoms seem to defy the doctor's expertise. Such encounters take time—a commodity that few doctors now have.

### Why Would a Patient, Previously Well-Regarded by the Physician, Be So Readily Dismissed?

Aspects of Lyme disease itself may contribute to the perplexing response of physicians. Patients generally appear healthier than they feel, and

symptoms are not only subjective but also quite variable, so that the patient presents differently from visit to visit. One day the symptoms appear more neurologic—ranging from sharp stabbing pains or shooting pains to dizziness, migraines, and problems with short-term memory.

On another day, the symptoms appear more rheumatologic, with migrating joint and muscle pains. On yet another day, the patient appears to be much better symptomatically. In addition, the patient may be cognitively impaired, making it hard for him or her to retrieve details of symptom history and present them in an organized way.

The lack of consistency in the patient's presentation may make the patient appear flaky and unreliable. The multiplicity of presentations may suggest to the physician that the underlying diagnosis is more likely a somatic symptom disorder, a stress disorder, or even a fabrication for secondary gain.

### How Does the Patient Feel?

Patients may come to feel like a pariah within the medical community, part of a marginalized group. Once "chronic Lyme disease" is in the medical chart, doctors and other health care providers may have an immediate negative bias: this patient is "bad news," won't respond well to interventions, and will have all kinds of preconceived and benighted notions of what is going on with them.

The experience of being disbelieved or even disliked by physicians can be not only demoralizing but also destructive to good patient care. Sensing the doctor's disbelief or distrust, the patient learns to screen his or her statements so as not to agitate the doctor and be further discredited. The net result is that the doctor ends up not hearing the full clinical picture and the patient ends up increasingly isolated.

Adding insult to injury, the same patient who has been told that "there is no such thing as chronic Lyme disease" may be dismayed and enraged to discover that past Lyme disease is an exclusion factor for life insurance.



The patient then asks, “If chronic symptoms after Lyme disease don’t exist or aren’t serious, then why is a past history of Lyme disease a reason for exclusion from life insurance?”

*The experience of being disbelieved and misrepresented over and over is inherently traumatizing.*

Others may find that even when treatments (such as intravenous antibiotics) are prescribed by their doctors, insurance companies refuse to pay, citing articles or calling upon “experts” who diagnose and treat Lyme disease according to very narrow criteria. The medical controversy has the effect of adding substantially to the financial burden of the illness on patients.

The experience of being disbelieved and misrepresented over and over is inherently traumatizing. Some patients, following eventual recovery from hard to diagnose and/or complex cases of Lyme disease, have identified this atmosphere of disbelief (and the resulting social isolation and self-doubt) as the single most stressful aspect of their illness experience.

From *Conquering Lyme Disease: Science Bridges the Great Divide*, by Brian A. Fallon, MD and Jennifer Sotsky, MD. Copyright ©2018. Reprinted with permission of Columbia University Press.

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Editor's note: Any medical information included is based on a personal experience. For questions or concerns regarding health, please consult a doctor or medical professional.