

PHENOMENAL COMPLEXITY

What are the symptoms of late-stage Lyme disease complex? I use the term ‘complex’ because the spectrum of symptoms are most often caused by the Lyme germ, *Borrelia burgdorferi*, AND other co-infecting pathogenic organisms that the ticks carry and transmit. With names such as *Babesia*, *Bartonella*, *Mycoplasma*, and *Anaplasma*, these pathogens can dramatically contribute to the degree of disease and complexity of diagnosis and treatment in infected individuals. So, as the immune system loses control of these bugs, they spread and cause inflammation, as well as release toxic molecules that cause symptoms and injury to cells and organs. With so many different possible combinations of infecting organisms and degrees of immune system compromise, the list of potential symptoms is very long. While one person might just have waxing and waning joint pains, another could be totally disabled with neuropathies that interfere with the ability to walk or even to stand. Some become blind from blood clots in the eyes and some are so fatigued that getting out of bed each day might not be possible. Many are plagued with the dreaded ‘brain fog’ and some develop what appear to be well-known psychiatric diseases such as bipolar disorder and severe depression. But, these patients need antibiotic treatment as much or more than anti-depressants and other psych meds. Many patients develop severe pain syndromes involving the back and legs, though involvement can be anywhere in the body. Some patients lose intellectual ability, hearing, the ability to sense heat from cold, and coordinated movements. Most develop insomnia, and many get disabling pain in their feet. Fevers, chills, sweats, dry cough, and body aches can make it seem that some sort of ‘chronic flu’ is going on. Lyme disease can cause life threatening cardiac abnormalities. And the list goes on. Some patients have only several symptoms and some have scores. It is no wonder that non-Lyme literate physicians either roll their eyes at the prospect of taking care of a Lyme patient or they simply refuse to believe that this constellation of symptoms is an active and treatable infectious disease. It is so much easier to believe that these patients have psychiatric disease (‘it’s all in your head’ type illness) or suffer the aches and pains of aging and a low pain threshold (whiners). It makes the doctor’s life so much easier. Just say no. And believe me, as I said before, I would not relish the notion of taking care of a patient with as complex a disease as my own.

And it’s not even that simple! We now know that in addition to the major germ types listed above, there are dozens to hundreds of genetic variations of these organisms. This introduces a level of diagnostic complexity that is mind-boggling. Physicians faced with a bad disease and complex long-term, sometimes dangerous treatment need as much diagnostic data as possible to justify a treatment plan. But testing for these pathogens is almost a lost cause to date. There are only a few tests for these bugs, and they miss most of the genetic variants. The tests are very meaningful and helpful when positive, but meaningless when negative. We simply cannot ‘rule out’ an infection with a negative test. Physicians who believe otherwise are wrong, if not downright negligent. But wait, there’s more!

It’s not just the bugs that determine our illness. Our unique immune system genetics and dysfunction play a large part creating the spectrum of symptoms we develop. It has been found that some genetic types tend to develop more severe disease than others, including subtypes that cannot get well. Some are more prone to creating antibodies that make us ill by attacking our own tissue and some have impaired ability to break down and excrete bacterial toxins. These are some of the reasons that one person’s Lyme disease doesn’t look another’s and why we need Lyme experts to manage sick patients. Lyme expertise will be discussed in a subsequent article.