

9. SIGNS AND SYMPTOMS OF LYME DISEASE

Lyme Disease, The Great Imitator

Lyme disease is known as the “Great Imitator.” Its list of symptoms is long and varied, and it can present differently in different individuals. A child with a diagnosis of autism may be showing the neurological manifestations of Lyme disease while an individual with a diagnosis of osteo- or rheumatoid arthritis may be showing more musculoskeletal manifestations.

Following is a list of illnesses that Lyme disease can mimic:

- Amyotrophic Lateral Sclerosis (ALS)
- Attention Deficit Disorder
- Autism
- Chronic Fatigue Syndrome
- Crohn’s Disease
- Encephalitis
- Fibromyalgia
- Interstitial Cystitis
- Irritable Bowel Syndrome
- Juvenile Arthritis
- Lupus
- Meningitis
- Motor Neuron Disease
- Multiple Sclerosis
- Obsessive-Compulsive Disorder

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- Parkinson's Disease
- Psychiatric Disorders (depression, bipolar, OCD etc.)
- Raynaud's Syndrome
- Rheumatoid Arthritis
- Scleroderma
- Sjogren's Syndrome
- Thyroid Disorders

And that is just a sampling.

Lyme disease can trigger autoimmunity, so some people will present with rheumatoid arthritis, lupus, Sjogren's, Hashimoto's thyroiditis or any number of autoimmune diseases. It may not be that these diagnoses are incorrect; it may just be that the Lyme infection has unbalanced the immune system sufficiently to trigger the autoimmune mechanism. Where there is autoimmune disease with sufficient evidence of Lyme disease (either through lab work or clinically), treating the Lyme will often improve, if not eliminate, the autoimmunity.

The key concept to grasp here is that of underlying cause. Western medicine has somehow distanced itself from the quest for discovery of the underlying cause of illness. As is the case with fibromyalgia or chronic fatigue syndrome, the diagnosis describes a set of symptoms but does not explain why they occur. Granted, often chronic fatigue syndrome is preceded by an acute viral illness, but even patients without the acute phase will be given the diagnosis of chronic fatigue simply based on, you guessed it, their symptom of chronic fatigue. Because Western medicine only looks at symptoms, many disease pictures with varying symptoms may be thought to be different diseases because they have different symptoms, when in fact the underlying cause may be singular: Lyme disease.

Clues to Lyme disease being causative are:

1. An individual has a constellation of symptoms involving multiple body systems.
2. Traditional diagnostic tests do not lead to anything conclusive or any clear diagnosis. ("Your tests came back normal. There's nothing wrong with you.")

3. An official diagnosis can be made (such as one of the above) but standard medical treatment does not have the expected benefit or result.
4. A therapeutic trial of anti-Lyme treatment (such as a course of antibiotics) leads to Herxheimer reactions and subsequent symptom improvement.

Since Lyme disease shows such a great variety of symptoms in every possible body system, it does not always fit any classic disease picture. Here is a fairly comprehensive list of the possible symptoms of Lyme disease (reproduced with permission from the Canadian Lyme Disease Foundation, www.canlyme.org):

Skin

- Rash at the site of the bite
- Rash on other parts of the body
- Raised rash, disappearing and recurring
- Striae (stretch marks) that may be red or purple
- Scratches on the skin (like cat scratches)
- Lumps (nodules) under the skin

Head, Face, Neck

- Unexplained hair loss
- Headaches, mild or severe
- Seizures
- Pressure in head, white matter lesions in brain (MRI)
- Twitching of facial or other muscles
- Facial paralysis (Bell's palsy)
- Tingling of the nose, tongue, or cheek
- Facial flushing
- Stiff or painful neck
- Jaw pain or stiffness
- Dental problems (unexplained), tooth pain
- Sore throat, clearing throat a lot, phlegm, hoarseness, runny nose
- Difficulty swallowing, feeling as if something is stuck in the throat

Eyes/Vision

- Double or blurry vision
- Increased floaters
- Pain in the eyes, or swelling around the eyes
- Hypersensitivity to light
- Flashing lights
- Phantom images in the periphery of vision

Ears/Hearing

- Decreased hearing in one or both ears, plugged ears
- Buzzing in the ears
- Pain in the ears, oversensitivity to sounds
- Ringing in one or both ears

Digestive and Excretory Systems

- Diarrhea
- Constipation
- Irritable bladder (trouble starting, stopping)
- Interstitial cystitis
- Upset stomach (nausea or pain)
- GERD (gastro esophageal reflux disease)

Musculoskeletal System

- Bone pain, joint pain or swelling, carpal tunnel syndrome
- Stiffness of joints, back, neck, tennis elbow
- Muscle pain or cramps
- Fibromyalgia
- Tendonitis

Respiratory and Circulatory Systems

- Shortness of breath
- Air hunger - cannot get full/satisfying breath
- Chronic cough
- Chest pain or rib soreness
- Night sweats or unexplained chills
- Heart palpitations or extra beats
- Endocarditis

- Heart blockage

Neurological System

- Tremors or unexplained shaking
- Burning or stabbing sensations in the body
- Weakness, peripheral neuropathy or partial paralysis
- Pressure in the head
- Numbness in the body, tingling, pinpricks
- Poor balance, dizziness, difficulty walking
- Increased motion sickness
- Light-headedness, wooziness

Psychological/ Psychiatric

- Mood swings, irritability, bipolar disorder
- Unusual depression
- Disorientation (getting or feeling lost)
- Feeling as if you are losing your mind
- Over-emotional reactions, crying easily
- Too much sleep, or insomnia
- Difficulty falling or staying asleep
- Narcolepsy, sleep apnoea
- Panic attacks, anxiety
- Obsessive-compulsive traits

Cognitive

- Memory loss (short or long term)
- Confusion, difficulty in thinking
- Difficulty with concentration or reading
- Speech difficulty (slurred or slow)
- Word finding difficulty
- Stammering speech
- Forgetting how to perform simple tasks

Reproduction and Sexuality

- Loss of sex drive
- Sexual dysfunction
- Unexplained menstrual pain, irregularity

- Unexplained breast pain, discharge
- Testicular or pelvic pain
- Vulvodynia

General Well-being

- Phantom smells
- Unexplained weight gain or loss
- Extreme fatigue
- Swollen glands/lymph nodes
- Unexplained fevers (high or low grade)
- Continual infections (sinus, kidney, eye, etc.)
- Symptoms seem to change, come and go
- Pain migrates (moves) to different body parts
- Early on, experienced a “flu-like” illness, from which you have not recovered completely
- Low body temperature
- Allergies/ chemical sensitivities
- Increased effect from alcohol and possibly more intense hangovers

That is quite an impressive list for such a tiny bacteria, but it is a true representation of what Lyme sufferers experience. If asked to check the boxes on a list, many Lyme patients would have 30 or 40 of the above checked.

What makes it all the more devastating for Lyme sufferers is that often-times they do not appear as sick as they really are. Certainly, on the inside, they feel like death warmed over, but outwardly they do not have any major observable manifestations. In fact, I often hear stories of their closest family members, co-workers and friends saying, “But you look so good. Surely you’re not that sick?” It is another reason why doctors miss the gravity of their situation; their outward presentation does not always match their inward experience.



Can You Guess the Disease?

Given what you now know about Lyme can you tell which disease is being described?

#1 Who Am I?

I could potentially put you in a wheelchair. When I produce some numbness and tingling, you'll probably go and see a neurologist. They will do an MRI and tell you that you have white lesions on your brain, but they will also tell you that there is not too much you can do about it. Or, they may find nothing, and suggest you see a counselor for hypochondria, so you may spend years thinking you are crazy and have no real health problems.

#2 Who Am I?

I make you really, really tired. I mean really tired. It's easy to think of me as something that lingers after a more acute illness. I make it so that you just can't bounce back. The fatigue is overwhelming, and your doctors tell you that you are just doing too much. They suggest that perhaps you need a vacation, or to slow down at work. You know it's more than that, but your blood work doesn't show any real problems and I make it look like nothing is really wrong with you. Mostly you're just tired and wondering if you'll ever get your spark back.

#3 Who Am I?

Within a few months, I can take you from a healthy, happy individual, to one completely unable to care for yourself. I sap your muscle strength and ability to move. I'll impact your legs and arms, and you will require help to move around. Later, when you are lying in bed, you'll need help lifting your arms and being fed. I might seriously impact your ability to eat, and even breathe. Ultimately, I may take your life.

#4 Who Am I?

I give you headaches, and I make you tired. You are grumpy and irritable all the time. I give you night sweats. Your other female friends go through similar things, but somehow this seems different. I work in cycles so

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every four weeks it seems worse, but I'm also making you sick at other times too, so it doesn't quite make sense. You see your ob-gyn and she checks your hormones, and they may be off so she gives you prescription hormones. You take them but I don't go away.

#5 Who Am I?

I make you hurt all over. Your muscles just ache and it's hard to get any relief. You are really tired, too, and proper and refreshing sleep seems to be elusive. I make you feel sick and tired, but it looks as if there's nothing wrong with you. Your doctors tell you that you're depressed and want to put you on anti-depressant medication. It helps a bit so you think that you might be on the right track, but then you start forgetting things and words are harder to put together. You wonder if it's because of the medications so you stop them, but nothing changes. Every day you wake up exhausted no matter how many hours you've slept.

#6 Who Am I?

I make your joints very sore and stiff. They are swollen, they are hot to touch, and they are red. I take the fun out of life because I stop you from being able to move around too much. Certainly sports and fitness are out of the question. I trick you because you feel well enough to be active, but your joints just won't allow it. You go to the doctor and he does some labs and says, "Yes, you have an illness." Then he tells you the treatment is steroids to combat the inflammation. He doesn't know you have an infection and that immune suppression will make you worse in the long run. In desperation you say yes and it helps then, but over time, things get worse. You gain 20 kilos out of nowhere, and sink into depression.

#7 Who Am I?

You have a small child, and you think your world is just perfect, but you notice your child is not hitting his milestones. Development seems delayed. It's your first child so you don't think too much of it, but then you realize that it's not quite right. You take your little guy to the pediatrician who assesses him and says that there is indeed a problem, although from

that point he doesn't seem to have too many ideas for solutions. You go home devastated, thinking that this is just something you will have to live with and adapt to the best you can.



Here is what these cases have been diagnosed (and possibly misdiagnosed) as:

1. Multiple sclerosis.
2. Chronic fatigue syndrome.
3. Motor neuron disease.
4. Female hormone imbalance.
5. Fibromyalgia.
6. Rheumatoid arthritis.
7. Autistic-spectrum disorder.

So how did you do? Did you recognize the above descriptions as some commonly diagnosed diseases and syndromes? What appears to be one disease may actually be Lyme disease in disguise, and so in the abovementioned cases, the patients' recovery was jeopardized by a faulty diagnosis.

Symptoms of Co-infections

We have already established that in many cases Lyme disease actually involves a range of different microbes (called "co-infections") such as *Borrelia*, *Bartonella*, *Babesia*, *Ehrlichia* and *Rickettsia*. While there is significant overlap between the symptoms of each one, there are also a few clues that can help determine which co-infections are present in an individual. Given that so much of the Lyme diagnosis is based on a clinical picture, health practitioners should understand the co-infections and their hallmark symptoms in order to determine which treatments will best help their patient.

Borrelia

- Gradual onset of symptoms
- Multi-system – e.g. joint pain along with cardiac involvement; cognitive deficits with fatigue and muscle/ joint pain
- Migratory pain from joint to joint
- Fatigue and lethargy, worse in the afternoon
- Four-week cycles
- Stiff, crackly joints
- Headaches originating in the neck
- Slow response to treatment with initial flare (Herxheimer reaction), improvement over weeks with monthly symptom flare
- EM rash in 25% to 50%

Bartonella

- Gradual onset of initial illness
- Central nervous system symptoms out of proportion to musculoskeletal
- CNS irritability including muscle twitches, tremors, insomnia, seizures, agitation
- Anxiety, severe mood swings, outbursts and antisocial behavior; OCD traits
- Headaches – feel like ice picks in the head
- Gastritis or abdominal pain, bowel problems (IBS)
- Tender sub-cutaneous nodules along the extremities, especially the outer thigh, shins, and triceps
- Occasional lymphadenopathy (swollen, enlarged lymph nodes)
- Striae or stretch marks that are new, out of place, can be white or red/ purple in color
- Pain in the sides and back of the ribs
- Pain in soles of the feet, painful to walk in the morning
- Tachycardia (rapid heart beat)
- Photophobia (light sensitivity)
- Rapid response to treatment but a rapid return of symptoms if treatment is stopped too early

Babesia

- Night sweats and sometimes day sweats as well
- Shortness of breath, air hunger, sighing
- Dry, chronic cough
- Fullness in the throat, difficulty swallowing
- Severe headaches - dull, all over head, feels like head is in a vice
- Dizziness, light-headedness
- Capillary angiomas especially on breasts
- Vasculitis (red skin with white splotches)
- Hormone imbalance
- Easy bruising
- Burning symptoms
- Head/ tooth/ sinus/ jaw symptoms
- Bell's palsy
- Nausea
- Ear ringing
- Blurry vision
- Vivid/ violent dreams, nightmares
- Flushing
- Flare-ups every 4-6 days
- Failure to respond to Lyme treatment
- Feeling of spaciness, wooziness, and impending doom

Ehrlichia/ Anaplasma

- Rapid onset of initial illness
- Headaches – sharp, knife-like, and often behind the eyes
- Muscle pain, not joint pain, can be mild or severe
- Neurological symptoms – seizure disorders, shooting pains
- Tendon pain
- Pain in the right upper quadrant of the abdomen
- Low WBC count, elevated liver enzymes
- Rapid response to treatment

Rickettsia

- Fever/ chills
- Headaches

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- Confusion
- Aching muscles
- Gastrointestinal symptoms – nausea, loss of appetite
- Swelling of lymph nodes
- Malaise