

What Every Social Worker Should Know About Lyme Disease

by Jane Sloven, LCSW, BCD

Social workers in the field of psychotherapy are trained to follow clues and unravel intra-psychic mysteries but the stealth invasion of the spirochete *Borellia burgdorferi*, responsible for the tick-borne illness, Lyme disease – can stump the most observant clinician. Lyme and its co-infections (*Babesia*, *Ehrlichia*, and *Bartonella*) predominantly attack the nervous and musculoskeletal systems. They can evade detection, mimic other diseases, and disable victims with chronic, unremitting pain. One of their most devastating characteristics, however, may be their tendency to masquerade as psychological and emotional illnesses.

Brian Fallon, M.D., MPH., and psychiatrist, Director of The Center for Neuroinflammatory Disorders and Biobehavioral Medicine and Director of The Lyme and Tick-Borne Disease Research Center at Columbia University, evaluates patients through MRI or SPECT brain scans, neuropsychological testing and interviews. He and others who treat tick-borne illness have observed these symptoms: depression, anxiety, depersonalization, fatigue, insomnia, cognitive confusion, attention deficits (auditory and visual), OCD, sensory hyperarousal syndromes (light, sound, smell, vibration), complex partial seizures, appetite loss, agoraphobia, déjà vu, musical hallucinations, poor frustration tolerance, mood swings, memory problems, stuttering, word reversal, and spatial or geographic problems. Physical symptoms of Lyme and co-infections can include numbness and tingling, tremors, roving pain, nerve pain, chills and sweats, gastrointestinal problems, headaches, hearing impairments and visual distortions.

I have seen a number of clients with such symptoms who were eventually diagnosed with Lyme and co-infections. These are some examples.

A client in her fifties complained of irritability, fatigue, depression, anxiety and cognitive and concentration difficulties. When conjoint treatment stalled, there was no improvement with anti-depressants, and her physical pain worsened, it was clear that something else was going on – that something else was Lyme and *Babesia*.

An educator in her sixties described fatigue, insomnia, depression, and difficulty completing work tasks. Her disclosure of embarrassing spelling errors and word reversals led to further exploration. An avid gardener, she'd attributed the strange pains in her wrists and arms to yard work. She tested positive for Lyme and *Babesia*.

A young woman in treatment for anxiety and relational issues suddenly developed buzzing, vibrating sensations, hypersensitivity to sound and light, numbness in her arms and legs, and depersonalization. She described burning sensations on her skin (Lyme sufferers call it rug-burn) night sweats and chills. She tested positive for Lyme and *Babesia*.

The Maine Center for Disease Control and Prevention has noted a 5-7% annual rise in the number of reported Lyme disease cases, which they consider significant. The 2006 total, 338, was the highest since surveillance began, and it was reported in 13 of 16 Maine counties. York and Cumberland accounted for almost 68%, but rates were high in Lincoln and Knox. Months of highest risk are June, July, August, October and November. Geoff Beckett, Assistant State Epidemiologist, says tick populations are moving east and up the Kennebec, Penobscot, and Androscoggin river valleys in Maine. He said *most cases are not reported* – both here and nationally – *because they're not diagnosed*.

The Center for Disease Control (CDC) in Atlanta reported 64,382 cases between 2003 and 2005 – from 46 states and the District of Columbia. Approximately 20,000 new cases are reported annually. Lyme is considered endemic in northeast states from Maryland to Massachusetts.

The clients I've described tested positive and received antibiotics. Other clients tested positive but weren't treated because their physicians did not believe they had Lyme disease. *That is not unusual*. Noted author, Amy Tan, had a long and difficult journey to diagnosis and treatment. See her website for details.

Continued on page 9

Continued from page 8

In reality, diagnosis and treatment are confusing. Many people never see a tick, never develop classic symptoms – a bulls-eye rash, high fever, flu like symptoms, or Bell's Palsy. Roving pain and swollen joints can be confused with rheumatoid arthritis, or both conditions may co-exist. Treatment may have to proceed without any laboratory confirmation – based on signs and symptoms, because laboratory testing cannot detect Lyme until four to six weeks after infection – and often can't detect it after that. Both the type of laboratory testing and its interpretation are subjects of contention.

Different physician groups, such as the Infectious Disease Society of America (IDSA), and The International Lyme and Associated Disease Society (ILADS), have looked carefully at peer-reviewed literature on tick-borne illness and come to radically different conclusions. Their published guidelines have entirely different approaches to diagnosis and treatment.

The IDSA and The American Academy of Neurology have published similar guidelines. They recommend 14 to 28 days of antibiotic treatment. They believe most patients are cured after 28 days, and that persistent infection after that treatment regimen is rare. They identify symptoms that exist following completion of the prescribed regimen as post-Lyme syndrome, and assert that there is no reliable evidence to support longer courses, varied classes, or combinations of antibiotics. They believe that serious risks and side effects of longer antibiotic treatment outweigh any potential benefit – especially when diagnosis is based exclusively on clinical signs and symptoms. The majority of physicians rely on the IDSA guidelines, and insurers utilize them to determine reimbursement for medication.

In contrast, the ILADS views Lyme disease as a persistent, at times chronic infection, often complicated by co-infections. They believe that chronic Lyme may be difficult to eliminate, require extended treatment with antibiotics – intravenously, intramuscularly, or orally, and often in high doses or combinations of different classes of antibiotics. ILADS guidelines emphasize individualized treatment based on the clinical picture. They believe that continuing symptoms can indicate active infection, and argue that the risks of failing to treat active infection can be far worse than the risks of over-prescribing. Lyme can affect every organ system, and although it is rare, Lyme can be fatal.

This is all very complicated. Why does it matter to social workers?

If our focus is clinical and we aren't aware of Lyme's neuro-psychiatric symptoms, we risk being confounded by our clients' lack of progress, might miss important clues, or pursue ineffective interventions. We might be sidetracked if physicians interpret client behavior as somatization or malingering, diagnoses which could compound clients' suffering. We may become triangulated and confused ourselves if our client has more than one physician and they disagree on diagnosis and treatment.

Whether our social work focus is community organizing or psychotherapy, it would be important to know of patient advocacy groups, such as the Lyme Disease Association (LDA). We might advocate for more dialogue, mediation, even collaboration between IDSA and ILADS physicians, instead of increasingly antagonistic interactions that benefit no one, least of all people who are seriously ill. We might campaign for more research, more accurate testing. We might work to empower clients to advocate for patient-centered diagnosis, treatment and care. And finally, as I know all too well, any of us can become infected, and the struggle then becomes our own.

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