



Living with Lyme disease:

The nurse's role in patient care

Learn how to recognize posttreatment Lyme disease syndrome, which occurs when Lyme disease symptoms last for more than 6 months after the infection is gone.

By Lucy Adams; Michael M. Evans, PhD, MEd, RN, ACNS, CMSRN, CNE; Kiernan Riley, BSN, RN; Kaléi Kowalchik, BSN, RN; Megan Lucey; and Logan DeSanto

LA, a 20-year-old female, presents to the ED with complaints of fever, fatigue, body aches, headache, and a rash on her left lateral abdomen for 3 days. She has no medical history except for a sports-related ankle injury last year that was resolved with physical therapy. She's currently a student at a local university in the Northeast region of the US, where she's studying nursing and playing soccer and basketball. The patient doesn't take any medications and has no allergies.

Ms. A's vital signs are temperature, 100.8° F (38.2° C); pulse, 120 beats/minute; respirations, 18 breaths/minute and shallow; BP, 128/84 mm Hg; and oxygen saturation, 98% on room air. She complains of generalized body aches at a 5/10 on a 0-to-10 pain rating scale. Her skin color is pale but warm to touch. She's awake, alert, and oriented times four and denies any other complaints except for a headache and feeling tired all the time.

Upon evaluation, both the ED physician and nurse discover an 8-cm by 6-cm

red, bullseye-appearing rash (erythema migrans) on the patient's abdomen. She denies any pain or pruritus at the site. Upon further questioning, the nurse discovers that Ms. A works in an outdoor setting and lives in a rural area, leading the nurse and the physician to feel that the patient may have been bitten by a deer tick and have Lyme disease.

After receiving orders from the ED physician, labs are drawn for an enzyme-linked immunosorbent assay test, complete blood cell count, sedimentation rate, and a complete metabolic panel. A 20-gauge I.V. is started in the patient's left antecubital fossa and normal saline solution is administered at 125 mL/h to help with hydration because she has had a fever for several days. Acetaminophen 650 mg by mouth is prescribed and the patient is started on doxycycline 100 mg by mouth twice a day for 3 weeks. Ms. A is discharged from the ED after receiving 2 L of I.V. fluids and encouraged to rest and follow up with her primary care provider or to return to the ED if symptoms worsen.



Ms. A's blood work confirms the diagnosis of Lyme disease. Upon completion of the antibiotic regimen, she's still experiencing fatigue and muscle aches even though the rash and fever have resolved, and her sedimentation rate remains elevated. The primary care provider and office nurse are suspicious that the patient has posttreatment Lyme disease syndrome (PTLDS).

Ms. A begins a regimen of massage and physical therapy to help improve her symptoms, and a referral is made to a rheumatologist for further evaluation. Ibuprofen 600 mg by mouth every 6 hours as needed is prescribed for joint pain and she's instructed to take the medication with food. Education is also provided on how to avoid future tick bites through proper use of repellent, clothing, and self-body exams. The nurse makes a follow-up appointment for 6

weeks to assess progress with the treatment plan.

Lyme disease 101

Lyme disease is a common, tick-borne illness caused by the bacterium *Borrelia burgdorferi*, which is carried by black-legged ticks. Because these ticks carry the Lyme disease bacterium, a bite from one tick can transmit it and cause Lyme disease. The tick needs to be attached to an individual for 36 to 48 hours for transmission of the bacterium to occur. In 2015, 38,069 confirmed and probable cases of Lyme disease were reported. Most prevalent in the northeastern US, the highest number of confirmed Lyme disease cases in 2018 were in Pennsylvania, New Jersey, New York, and Connecticut.

After the Lyme disease bacterium is transmitted, the first presenting symptom is often a rash known as erythema migrans at the site of the tick bite. This rash is commonly referred to as a bull's-eye rash because of its distinct red, ring-shaped appearance (see *Picturing Lyme disease*). The rash can develop 3 to 30 days after the tick bite and is rarely painful. Not everyone with Lyme disease develops a rash; however, it's a common symptom that occurs in 70% to 80% of infected people. If a rash doesn't develop, other symptoms, such as a fever, chills, headache, swollen lymph nodes, and joint aches, may occur. When joints are affected by Lyme disease, swelling and severe pain can occur in large joints like the knees.

Later symptoms of Lyme disease include facial palsy, heart palpitations, headaches, neck stiffness, arthritis with swelling, episodes of dizziness with shortness of breath, nerve pain, and additional erythema migrans rashes on other areas of the body. A potentially fatal complication of Lyme disease is Lyme carditis, in which the Lyme disease bacterium invades cardiac tissue and interferes with normal cardiac function (see *Lyme carditis*).

Picturing Lyme disease



Source: Engleberg NC, Dermody T, DiRita V. *Schaechter's Mechanisms of Microbial Disease*. 5th ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2012.

A diagnosis of Lyme disease involves both the identification of signs and symptoms and lab testing, including testing for the presence of antibodies, which can take weeks to develop. An antibody test may come back negative if a person was only recently infected.

After diagnosis, the recommended treatment for adults is either doxycycline 100 mg orally twice daily for 10 to 21 days or amoxicillin 250 to 500 mg orally three times daily for 10 to 21 days. For children, the recommended dosages are reduced to doxycycline 1 to 2 mg/kg twice daily or amoxicillin 25 mg/kg three times daily for 14 days. For patients who are allergic to doxycycline or amoxicillin, cefuroxime may be prescribed. It's crucial that patients be instructed to complete the full course of antibiotics even if they're feeling better. If Lyme carditis is present, a temporary pacemaker or I.V. antibiotics may be needed.

If individuals with Lyme disease are treated with antibiotics during its early stages, typically within 1 to 4 weeks after transmission, they're usually able to recover quickly and completely. However, approximately 5% of those with Lyme disease don't recover completely and develop PTLDS, in which lingering symptoms of fatigue, pain, or joint and muscle aches last for more than 6 months.

When Lyme disease symptoms linger

The cause of PTLDS is unknown, but it's believed that the Lyme disease bacterium can cause an autoimmune response, resulting in symptoms that persist after the infection is gone. There's no proven cure for PTLDS, and the symptoms don't respond to antibiotics. In fact, studies have shown that there are no clear and lasting benefits of using prolonged antibiotic therapy for patients still experiencing Lyme disease symptoms, such as fatigue and joint pain, after their course of antibiotics has been completed. Symptoms can be alleviated by antidepressants, analgesics, complementary and alternative

medicine (CAM) therapies, psychotherapy, pregabalin, and gabapentin.

Pain relief

Lyme arthritis is mainly seen in patients when Lyme disease is untreated or not caught soon enough for antibiotics to be effective; however, muscle and joint aches are common symptoms associated with early Lyme disease. Patients who are experiencing pain and swelling in their muscles and joints can benefit from using nonsteroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen, aspirin, and naproxen sodium, to manage their symptoms. NSAIDs work by reducing inflammation in the joints and muscles, which can help ease swelling and pain.

For patients with PTLDS, different types of medications are recommended for different types of pain. For example, patients experiencing arthritic pain can benefit from medications, such as amitriptyline, cyclobenzaprine, and serotonin and norepinephrine reuptake inhibitors like duloxetine. For patients experiencing neuropathic pain, medications, such as gabapentin and pregabalin, have been shown to help. When musculoskeletal pain is experienced, patients may benefit from naltrexone, the use of heat to loosen muscles and increase flexibility and circulation, and the use of ice to dull pain and reduce inflammation. It's recommended that ice be used first to ease pain and then heat applied afterward

Lyme carditis

- Lyme carditis, which occurs in about 1% of Lyme disease cases, results when the *B. burgdorferi* bacterium enters the heart tissues.
- Lyme carditis can interfere with the heart's electrical conduction, causing heart block and symptoms, such as chest pain, fainting, shortness of breath, light-headedness, and heart palpitations.
- Question patients with Lyme disease or possible Lyme disease to assess for cardiac related symptoms. For patients with unexplained cardiac symptoms, inquire about possible tick exposure.
- Treatment for Lyme carditis is oral or I.V. antibiotics for 14 to 21 days. The type and route of antibiotics will depend on the severity of inflammation. If Lyme carditis is suspected, antibiotics should be started immediately instead of waiting for diagnostic confirmation. Ensure that the patient completes the course of antibiotics.



Signs and symptoms

Lyme disease: Early stages

- Erythema migrans at the site of the tick bite
- Fever/chills
- Headache
- Swollen lymph nodes
- Joint aches
- Fatigue

Lyme disease: Late stages

- Facial palsy
- Heart palpitations
- Headache
- Neck stiffness

- Arthritis with swelling
- Dizziness
- Shortness of breath
- Neuropathic pain
- Additional erythema migrans rashes on other areas of the body
- Lyme carditis

PTLDS

- Fatigue
- Neuropathic pain
- Musculoskeletal pain
- Lyme arthritis

cheat
sheet

to ease stiffness. For lasting pain, heat is recommended but is often dependent on the patient's preference.

CAM therapies

For patients experiencing PTLDS or chronic symptoms of Lyme disease, there are many CAM therapies available (see *CAM therapies for PTLDS management*). Chronic symptoms can impact the patient's physical and psychosocial well-being. The goal of intersecting pharmacologic and nonpharmacologic treatments is to manage symptoms, increase function, and improve quality of life for patients with PTLDS. Patients with persistent symptoms of Lyme disease may require multidisciplinary care.

Before treatment of PTLDS, it's imperative to rule out other chronic illnesses, such as fibromyalgia, depression, and/or chronic fatigue syndrome, to ensure that the patient's medical needs are met.

Patient education

When Lyme disease symptoms persist despite antibiotic treatment, PTLDS becomes relevant for the patient. Nurses must be aware that symptoms, such as fatigue, bone or joint pain, and difficulty thinking, can continue for 6 months or longer. Educate patients about this aspect of the disease and instruct them to report

any symptoms to their primary care provider. Also, be empathetic to the patient's frustration or other feelings associated with the persistence of PTLDS.

Early recognition and prevention

Lyme disease can be difficult to properly diagnose due to the vague nature of symptoms. A thorough physical assessment and patient history should always be completed. Examples of selective history questions include, "Have you spent any time outdoors in the woods recently?" "Have you noticed any new fatigue or joint pain recently?" "Have you traveled anywhere recently?" Nurses should be aware of the places that are likely to lead to tick exposure, as well as the signs and symptoms of Lyme disease.

During the early stages of Lyme disease, the presenting symptoms can include fatigue, joint pain, and fever. Nurses in a variety of settings should be aware of the symptoms that are likely to appear early on to prevent the disease from progressing into later stages. For example, erythema migrans is generally the classic, first sign that develops at the location of the tick bite. By being mindful of these early manifestations, the patient can begin treatment as soon as possible.

Prevention methods and patient teaching are aimed at avoiding initial transmission of the Lyme bacterium from an infected tick. One method of preventing transmission of the *B. burgdorferi* bacterium is the use of a repellent with ingredients specifically formulated for tick prevention. Teach patients to use insect repellent containing diethyltoluamide, picaridin, oil of lemon eucalyptus, or para-menthane-3,8-diol before going outdoors. The 0.5% insecticide permethrin can be applied to clothes before any potential tick exposure.

In general, people should be mindful of going into wooded areas, bushes, or areas with high grass because these are common areas for tick exposure. Articles of clothing, such as high socks, long pants,

CAM therapies for PTLDS management

Mental health considerations

Cognitive behavioral therapy (CBT)

CBT is a psychological intervention that uses problem-solving approaches to reshape an individual's cognitive thinking, emotional regulation, and coping mechanisms. It can be used to manage the perceived stress of living with a chronic illness and allows patients to verbalize and work through feelings about their disease process.

Mindfulness

Mindfulness is a cognitive-based therapeutic intervention that creates purposeful physical, emotional, and spiritual self-awareness. It encourages individuals to process and control symptom burden and self-perception. This therapeutic intervention has been shown to reduce physical and psychological strain in patients living with chronic symptoms, such as pain, fatigue, stress, anxiety, and depression.

Support groups

Support groups, online or in-person, allow patients to express their experiences and obtain encouragement and guidance through informal communication. Support group participation creates an avenue for patients with Lyme disease and other tick-borne diseases to connect with other people who are affected.

Exercise and physical therapy

Exercise

Exercising can increase energy and overall feelings of well-being. Participating in exercise can help teach patients how to work through physical symptoms, such as chronic pain and fatigue. Light-to-moderate aerobic exercises, such as yoga, walking, and swimming, are recommended to decrease joint and muscle stiffness.

Biofeedback/physical therapy

Biofeedback uses electrical sensors to relax muscles to reduce pain and other physiologic symptoms associated with PTLDS. The implementation of massage therapy can stimulate blood flow and regulate oxygenation to local tissues to reduce inflammation and pain.

Diet

Diet control, along with other therapeutic interventions, can increase immune function and decrease the severity of symptoms in patients with PTLDS. Researchers recommend anti-inflammatory diets. Encourage patients to increase their intake of fruits and vegetables and decrease consumption of processed sugars.

Energy conservation

Encouraging patient rest and relaxation is important to avoid physical strain on the body and avoid exacerbation of chronic symptoms.

long-sleeved shirts, and gloves, should be worn to cover exposed body parts when in areas where tick exposure is probable.

Additionally, individuals should check their entire body for ticks when returning from being outdoors, including warm areas on the body, such as the armpits, groin, and under the breasts. Teach patients to report any rashes or lumps that appear on the skin after being outdoors.

Barriers to care

Barriers to care for patients with Lyme disease exist within the contexts of diagnosis, treatment, and prevention.

One qualitative study identified diagnosis delays as barriers to effective care, including misattribution of symptoms, overreliance on the presence of a “bulls-eye” rash, and the intermittency of Lyme disease symptoms. Even within correct lab tests, there’s a 50% chance for an incorrect diagnosis. Unfortunately, testing becomes more accurate as Lyme disease progresses from early to late stages.

Another significant barrier to treatment is health insurance status. Because Lyme disease can be costly for uninsured patients, lack of insurance or poor insurance can contribute to delayed or missed



key points

Nursing interventions: Patient teaching

Teach patients:

- to wear a long-sleeved shirt and pants, spray with appropriate solution, inspect their bodies, and report any rashes or lumps that appear on the skin after being outdoors
- to complete their full course of antibiotics if prescribed for diagnosed Lyme disease even if they're feeling better to prevent antibiotic resistance
- about PTLDS and available treatment options.

care and individuals not able to access care for PTLDS.

A recent study discussed significant barriers to Lyme disease prevention, particularly when focusing on tick research. There isn't significant incentive to conduct funded Lyme disease research, including vaccines for people at risk for Lyme disease. This creates a lapse in evidence-based information and practice for nurses to disseminate to those at risk and implement on a community level.

Unfortunately, further evidence-based information is limited related to barriers to Lyme disease diagnosis, treatment, and prevention. It's necessary for these barriers to continue to be explored so we can understand how to overcome them. As it stands, barriers to Lyme disease management are a gap within the literature base.

Keen assessment needed

The nurse's role when caring for patients with Lyme disease includes being aware of the vague nature of symptoms to quickly work toward a diagnosis to prevent further complications from the disease. When symptoms continue to persist after antibiotic treatment, nurses should be aware of PTLDS. To encourage prevention, educating patients on common places for tick exposure is crucial so they can prepare by using the proper repellent and clothing. Although gaps in the literature do exist regarding barriers to diagnosis, treatment, and prevention,

nurses are in a unique position to care for patients with Lyme disease and those experiencing PTLDS by overcoming barriers to care and following best practices for treatment. ■

REFERENCES

- Adams DA, Thomas KR, Jajosky RA, et al. Summary of notifiable infectious diseases and conditions--United States, 2015. *MMWR Morb Mortal Wkly Rep*. 2017;64(53):1-143.
- American Psychological Association. What is cognitive behavioral therapy? 2017. www.apa.org/ptsd-guideline/patients-and-families/cognitive-behavioral.
- Baker PJ. A review of antibiotic-tolerant persisters and their relevance to posttreatment Lyme disease symptoms. *Am J Med*. 2020;133(4):429-431.
- Beng TS, Chin LE, Guan NC, et al. Mindfulness-based supportive therapy (MBST): proposing a palliative psychotherapy from a conceptual perspective to address suffering in palliative care. *Am J Hosp Palliat Med*. 2015;32(2):144-160.
- Centers for Disease Control and Prevention. Lyme carditis. 2020. www.cdc.gov/lyme/signs_symptoms/lymecarditis.html.
- Centers for Disease Control and Prevention. Lyme disease. 2021. www.cdc.gov/lyme/index.html.
- Centers for Disease Control and Prevention. Lyme disease maps: most recent year. 2019. www.cdc.gov/lyme/data-surveillance/maps-recent.html.
- Centers for Disease Control and Prevention. Post-treatment Lyme disease syndrome. 2019. www.cdc.gov/lyme/postlds/index.html.
- Centers for Disease Control and Prevention. Preventing tick bites. 2020. www.cdc.gov/ticks/avoid/on_people.html.
- Cleveland Clinic. Living with Lyme disease: how to promote long-term healing. 2019. <https://health.clevelandclinic.org/living-with-lyme-disease-how-to-promote-long-term-healing>.
- Cleveland Clinic. What's better for soothing arthritis pain? Ice or heat? 2019. <https://health.clevelandclinic.org/whats-better-for-soothing-arthritis-pain-ice-or-heat>.
- Columbia University Irving Medical Center Lyme and Tick-Borne Diseases Research Center. Treatment options. www.columbia-lyme.org/treatment-options.
- Eisen L, Stafford KC. Barriers to effective tick management and tick-bite prevention in the United States (Acari: Ixodidae). *J Med Entomol*. 2020;tjaa079.
- Envita. The 3 obstacles to neurological Lyme disease treatment. www.envita.com/lyme-disease/the-three-obstacles-to-neurological-lyme-disease-treatment.
- Global Lyme Alliance. Support groups. <https://global-lymealliance.org/support-groups>.
- Hirsch AG, Herman RJ, Rebman A, et al. Obstacles to diagnosis and treatment of Lyme disease in the USA: a qualitative study. *BMJ Open*. 2018;8(6):e021367.
- Lacout A, El Hajjam M, Marcy P-Y, Perronne C. The persistent Lyme disease: "True chronic Lyme disease" rather than "post-treatment Lyme disease syndrome". *J Glob Infect Dis*. 2018;10(3):170-171.
- Lantos PM. Chronic Lyme disease. *Infect Dis Clin N Am*. 2015;29(2):325-340.
- Leland DK. Book review: *The Lyme Diet: Nutritional*

Strategies for Healing from Lyme Disease by Nicola McFadzean, ND. LymeDisease.org. www.lymedisease.org/book-review-mcfadzean2-lyme-disease.

Mayo Clinic. Lyme disease. 2020. www.mayoclinic.org/diseases-conditions/lyme-disease/diagnosis-treatment/drc-20374655.

McGhee S, Visovksy C, Zambroski C, Finnegan A. Lyme disease: recognition and management for emergency nurses. *Emerg Nurse*. 2018;26(3):17-34.

Murphy M, Kontos N, Freudenreich O. Electronic support groups: an open line of communication in contested illness. *Psychosomatics*. 2016;57(6):547-555.

Puniewska M. Lyme disease 101. *Health*. 2020;34(6):61.

Rebman AW, Aucott JN. Post-treatment Lyme disease as a model for persistent symptoms in Lyme disease. *Front Med (Lausanne)*. 2020;7:57.

Regis College. Taking a look at Lyme disease: the rash, the origins and health care's responsibility. <https://online.regiscollege.edu/blog/taking-look-lyme-disease-rash-origins-health-cares-responsibility>.

Sanchez E, Vannier E, Wormser GP, Hu LT. Diagnosis, treatment, and prevention of Lyme disease, human granulocytic anaplasmosis, and babesiosis: a review. *JAMA*. 2016;315(16):1767-1777.

Sanchez JL. Clinical manifestations and treatment of Lyme disease. *Clin Lab Med*. 2015;35(4):765-778.

Schoen RT. Lyme disease: diagnosis and treatment. *Curr Opin Rheumatol*. 2020;32(3):247-254.

Ścieszka J, Dąbek J, Cieślak P. Post-Lyme disease syndrome. *Reumatologia*. 2015;53(1):46-48.

Skar GL, Simonsen KA. Lyme disease. StatPearls [Internet]. Treasure Island, FL: StatPearls Publishing; 2021.

Waddell LA, Greig J, Mascarenhas M, Harding S, Lindsay R, Ogden N. The accuracy of diagnostic tests for Lyme disease in humans: a systematic review and

on the web

American College of Rheumatology:

www.rheumatology.org/I-Am-A/Patient-Caregiver/Diseases-Conditions/Lyme-Disease

CDC: www.cdc.gov/lyme/index.html

Lyme Disease Association:

<https://lymediseaseassociation.org>

Mayo Clinic: www.mayoclinic.org/diseases-conditions/lyme-disease/symptoms-causes/syc-20374651

National Institute of Allergy and Infectious

Diseases: www.niaid.nih.gov/diseases-conditions/lyme-disease

meta-analysis of North American research. *PLoS One*. 2016;11(12):e0168613.

At The Pennsylvania State University College of Nursing, Lucy Adams is a Junior Honors Nursing Student, Michael M. Evans is the Assistant Dean of Undergraduate Nursing Education for the Commonwealth Campuses and an Associate Professor of Nursing, Kiernan Riley is a BSN-to-PhD Student, Kaléi Kowalchik is a BSN-to-PhD Student, Megan Lucey is a Sophomore Honors Nursing Student, and Logan DeSanto is a Junior Honors Nursing Student.

The authors and planners have disclosed no potential conflicts of interest, financial or otherwise.

DOI-10.1097/01.NME.0000753044.66974.b1



For 105 additional nursing continuing professional development articles related to infection topics, go to NursingCenter.com/CE.

Lippincott®
NursingCenter®

NCPD Nursing Continuing
Professional Development

INSTRUCTIONS

Living with Lyme disease: The nurse's role in patient care

TEST INSTRUCTIONS

- Read the article. The test for this nursing continuing professional development (NCPD) activity is to be taken online at www.nursingcenter.com/CE.
- You'll need to create an account (it's free!) and log in to access My Planner before taking online tests. Your planner will keep track of all your Lippincott Professional Development online NCPD activities for you.
- There's only one correct answer for each question. A passing score for this test is 7 correct answers. If you pass, you can print your certificate of earned contact hours and access the answer key. If you fail, you have the option of taking the test again at no additional cost.
- For questions, contact Lippincott Professional Development: 1-800-787-8985.
- Registration deadline is **June 7, 2024**.

PROVIDER ACCREDITATION

Lippincott Professional Development will award 1.5 contact hours including 0.5 pharmacology hour for this nursing continuing professional development activity.

Lippincott Professional Development is accredited as a provider of nursing continuing professional development by the American Nurses Credentialing Center's Commission on Accreditation.

This activity is also provider approved by the California Board of Registered Nursing, Provider Number CEP 11749 for 1.5 contact hours. Lippincott Professional Development is also an approved provider of continuing nursing education by the District of Columbia, Georgia, and Florida, CE Broker #50-1223. Your certificate is valid in all states.

Payment: The registration fee for this test is \$17.95.