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Association of Medical Microbiology and Infectious Disease Canada
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The Facts about Lyme disease: What You Need To Know

Q. If I am bitten by a tick will I get Lyme disease?

A. Not necessarily. The risk of getting Lyme from a tick depends on:

1. **The type of tick that has bitten you -** In Canada, blacklegged or western blacklegged ticks (also called deer ticks or Ixodes ticks) are the main types of ticks that transmit the infection.
2. **Whether the tick has the bacteria -** not all black legged ticks in Canada are infected. Check the maps on your Provincial website or the Public Health Agency of Canada's web site for up to date information: https://www.canada.ca/en/public-health/services/diseases/lyme-disease/risk-lyme-disease.html#map
3. **How long the tick has been attached.** The bacteria must move from the gut of the tick to its saliva glands in order to infect humans. This takes at least 24 hours to occur.

If the tick was infected, the longer the tick stays attached, the higher your risk of becoming infected. If the tick has been removed within a day (24 hours), the chances of getting the infection are very low.

Q. Do the bacteria that cause Lyme disease cause chronic infection after antibiotic treatment?

A. No. There are no studies at this time in humans that prove the bacteria that causes Lyme disease can survive in the body after antibiotic treatment as recommended by the Infectious Disease Society of America, AMMI Canada, the CDC in the US or the National Institute for Health and Care Excellence guidelines in the United Kingdom.

1. Oliveira CR, Shapiro ED. Update on persistent symptoms associated with Lyme disease. Curr Opin Pediatr. 2015 Feb;27(1):100-4.

Q. Are the tests used in Canada accurate?

A. Yes, these tests are very accurate except in detecting early infection. The current lab test for Lyme disease (something called serology) looks for antibodies that your body makes when exposed to the bacteria. It takes time for your body to make enough antibodies for the test to detect that you have been infected. This is true for all infections, not just Lyme disease. This is why the ability of the Lyme antibody test to pick up early infection is poor (it misses it 50% of the time). However, if you do not get treated, your body continues to react to the bacteria and develops more antibodies so that people who have infection for weeks to months (like those who have Lyme arthritis) are close to 100% likely to have a positive test. That means that if you

have had symptoms for months to years and have a negative antibody test done by a Canadian lab, Lyme disease is very unlikely.

Some laboratories in the US or Europe use alternative tests or read tests differently than what is recommended by expert laboratories in the US (the Centres for Disease Control (CDC)) and Canada (National Microbiology Laboratory (NML)). These alternative tests can have falsely positive results in over half of the patients tested. That means for every 100 people tested for Lyme disease, these alternative tests are positive in 50 people who do not have Lyme disease. This makes it impossible to say a positive result using these alternative tests is due to Lyme disease.

1. 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 Meta-Analysis of North American Research. PLoS One. 2016 Dec 21;11(12):e0168613.

2. Fallon BA, Pavlicova M, Coffino SW, Brenner C. A comparison of Lyme disease serologic test results from 4 laboratories in patients with persistent symptoms after antibiotic treatment. Clin Infect Dis. 2014 Dec 15;59(12):1705-10

Q. Why am I still tired and have pain after I have been treated for Lyme disease?

A. Most people who get treated for Lyme disease get better after recommended courses of antibiotic treatment. However, 10-15% of people can have ongoing symptoms such as fatigue, difficulty concentrating, or pain and are diagnosed with Post Treatment Lyme Disease Syndrome. It is not exactly clear why this happens in some people, and many researchers are looking into this, but it takes time for the body to heal and individuals get better without further antibiotic treatment.

1. Wills AB, Spaulding AB, Adjemian J, Prevots DR, Turk SP, Williams C, Marques A. Long-term Follow-up of Patients With Lyme Disease: Longitudinal Analysis of Clinical and Quality-of-life Measures. Clin Infect Dis. 2016 Jun 15;62(12):1546-1551

Q. Should people with chronic symptoms and a negative test for Lyme disease in Canada go to the United States to be diagnosed with Lyme disease and get treatment?

A. No. Testing for Lyme disease, with the antibody test used in Canada, is accurate in ruling out infection if individuals have had symptoms for months. Studies have shown that laboratories that use alternative tests or read tests differently than what is recommended by expert laboratories in the US (the Centres for Disease Control (CDC)) and Canada (National Microbiology Laboratory (NML)) can have very high rates of false positive results (over 50%). For patients who have persistent symptoms and negative tests in Canadian labs, positive results in these laboratories are most likely false-positive tests.

Other individuals are being told they have Lyme disease based on symptoms alone with no positive laboratory tests and may be given long and costly treatments that have not been shown to work or have been shown to be no better than taking a placebo. Patients and their health care providers need to look for other causes for the symptoms. A "false-positive" test result could also, in some cases, delay the diagnosis and treatment of the true cause of the individual's symptoms.

Q. **If long term antibiotics are not effective, why do we hear about people getting better with them?**

A. Although there are some reports of people getting better with prolonged courses of antibiotics, well designed studies looking at this have not shown that it works. In these studies, where people were given up to 70 days of antibiotics or placebo to treat their persistent symptoms, people felt better even when they received the placebo (like a sugar pill). The placebo effect is a well-known phenomenon, which is why it is important to do studies where the participants and the researchers do not know what medication is being given. Without these studies, we cannot be sure whether the reason people feel better is because of the drug treatment or the placebo effect.

Q. **Other than costing a lot of money, what is the down side to getting months or years of antibiotics?**

A. If you keep taking antibiotics when they have not been shown to work, you run the risk of side effects including allergic reactions, serious bowel infections, such as *C. difficile,* and infections with antibiotic resistant bacteria. While AMMI Canada does not support the use of prolonged courses of antibiotics to treat patients with persistent symptoms attributable to Lyme disease, we strongly encourage people suffering from these symptoms to see their healthcare provider to look for other possible causes and to work with their healthcare provider to come up with a plan to manage their symptoms.

Q. **Where can I find good quality information on Lyme disease?**

A. The internet can be a valuable source of information; it can also be difficult sometimes to tell what information is backed up by good science. Here are some reliable sites that can help answer your questions:

https://www.canada.ca/en/public-health/services/diseases/lyme-disease.html
https://www.niaid.nih.gov/diseases-conditions/chronic-lyme-disease
https://www.cdc.gov/lyme/faq/index.html
https://www.aldf.com/myths-about-lyme-disease/
https://www.nice.org.uk/guidance/ng95