

PE1662/Z

Anonymous submission of 14 February 2020

My Lyme disease experience

On holiday in central Europe, I lay on a towel for a few minutes of sunbathing beside a swimming pool (my legs were in contact with manicured cut grass). After a short time I sat up and found a tick attached to the side of my upper leg. The tick was carefully removed using the lifeguard's tweezers. It was only attached for a short time, and although I tried not to squeeze it as I removed it, I may have done so. I had no rash following the bite. Three weeks later I had stiffness between my shoulder blades and felt flu-like. I remembered the tick bite and after looking up information on the internet, I went to see my GP. The GP wanted a blood test done but did not prescribe antibiotics. (GP consulted Infectious Diseases who said that the tick needed to be attached for 24 hours for infection – GP phoned me to pass on this information). Symptoms got worse - numbness in face and tongue, aching muscles, headaches, feeling very tired. After several visits to GP I finally got antibiotics (6 weeks post bite) but only 100mg per day for 2 weeks instead of the then recommended 200 mg per day. I researched online and pointed out the error in dosage to the GP. I was then given 2 weeks of 200mg per day but was very unwell (brain fog, chills, twitches, vertigo, dizziness and terrible fatigue). Two blood tests carried out by NHS were both negative. I was bedbound and off work for three months. I slowly started to recover and returned to work. Symptoms returned in full shortly after my return to work. After some persuasion, my GP then gave 4 weeks 200mg per day of antibiotics. My symptoms were such that I was referred to Neurology and Infectious diseases. I had an MRI scan of my brain and my spinal cord. These proved inconclusive and no further treatment was offered. My symptoms continued. I sought a blood test in Germany through Armin labs. This came back positive for Borrelia, and two other tick-borne infections, which I had not been tested for by the NHS. At this point I realised I could not wait to be treated by the NHS and decided to seek treatment elsewhere. If I had not done this, I believe I would still be unwell today. After several years of treatment outside the NHS and at much personal expense, I am now in remission and back at work. If I had not taken action as quickly as I did to seek other help, I can't begin to imagine how my life would be today.

Trying to recover from Lyme involves huge personal effort and expense. Much of my time was taken up in researching the disease and how to get better. There was no doctor to point the way or to support me. I felt abandoned. I had no positive diagnosis within the health service. Unlike other chronic diseases, there is no public help-line or counselling service or support, yet this disease is devastating – physically, emotionally, socially – every aspect of life is affected.

Lack of public awareness about Lyme disease is prevalent in Scotland. This is then compounded by the poor knowledge of GPs. When I presented initially with a known tick bite and specific symptoms, I should have been treated straight away with antibiotics and not made to wait for a blood test. This is further compounded by

incorrect advice being given out by Infectious Disease consultants. I contracted the disease although the tick was only attached for 15 minutes. Again if the advice had been correct, I could have been treated shortly after being bitten and not had to endure such a long, hard and expensive road to remission.

This disease is only going to increase in prevalence. Please seize the opportunity to act now to improve treatment for patients with Lyme disease and associated tick-borne diseases in Scotland.