

Hello,

Thanks for covering Lyme disease in Woman's hour today. I have had Lyme disease for 8 years and it has irrevocably changed my life.

I have had to go to America to get adequate treatment as the NHS simply don't understand it. I was unable to walk following a tick bite on the west coast of Scotland in 2008. The doctors here were clueless, they told me it was a cold virus! I was a previously fit and well hillwalker and climber and now I had to crawl around my house because my legs wouldn't work. I had nausea, debilitating bouts of dizziness, insomnia, headaches, numbness, I was too weak to lift the kettle, so tired that I just wanted to sleep and stay in bed, I lost co-ordination and became very clumsy and then my mind started to go and I was unable to add up small numbers and forgot my pin number and how to drive. I have a PhD so when I was unable to even read a trashy women's magazine and changed from articulate to barely able to string a sentence together, I got really worried. It seemed the bacteria was in my brain. I never had a bullseye rash and in fact an estimated 50% of patient's don't see a rash.

My NHS tests continued to come back negative. I since learned that tests of the type used by the NHS miss around 42% of true cases, so they are not reliable and a negative test should not be used to rule out Lyme. I was totally abandoned by the NHS due to the negative tests, so I sought private diagnosis from a doctor who specialised in Lyme and his opinion -supported with positive private testing- was that I had neurological Lyme disease and that I needed extended courses of various antibiotics. I got remission after 19 months of this treatment, had a baby, was healthy for 2.5 years and then relapsed when my daughter was 18 months old. My previous doctor had now retired so I was forced to go abroad and I am now treated by an American specialist. I am now mostly healthy although things like the flu can set me back and allow the Lyme to flare once more.

My story is, unfortunately, all too typical. Lyme is far far more common than the official statistics suggest. A recent study in healthy blood donors in Scotland show that an average of 4.2% of Scottish donors have antibodies to the disease, so an estimated 218,400 Scottish people have been exposed to it. Some get sick, some don't and we don't have any good figures for the numbers who do get sick. It is a very under-diagnosed disease due to it mimicking many other conditions and the unreliability of the testing. Donated blood is not routinely screened for Lyme, there are no screening questions for donors regarding tick bites or Lyme and we know that the bacteria can survive the blood bank processing and storage. This is something we should be concerned about and yet nothing is being done, despite patient's repeatedly raising their concerns re this issue.

There are also concerns that Lyme can be transmitted from mother to baby in the womb and there is some data to support this. I was told by the NHS infectious diseases consultant I saw that 'this was not a concern' although the maternity hospital disagreed and gave me frequent ultrasound scans as some data suggests maternal Lyme infection can be associated with increased risk of miscarriage (of which I have had 3)s and babies who are born infected. Yet I was offered no NHS treatment to reduce these risks and had to pay privately for antibiotic treatment to prevent harm to my second child who was- fortunately born healthy and tested negative for Lyme.

People should be aware of the serious consequences that a single tick bite can bring. I would urge people to take the risks of tick bites very seriously indeed and use repellents, cover up, stick to paths and check for ticks regularly, removing them properly.

Best Regards,

***Dr Nicola Seal***

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