

Dear Woman's Hour,

Thank you for giving the subject of Lyme disease an airing on Radio 4 a couple of weeks ago. I understand that this email will sound a bit churlish but, rather than try to dress up what I feel about the programme in euphemistic language, I would rather be straight. Please understand I am speaking from a place of concern for others and from a life-time of listening, and trusting, Woman's Hour. Many of us felt let-down by your programme and even more suspicious that there is some influence preventing the serious media (Radio 4, BBC TV prime-time, etc) from telling the real situation behind Lyme disease in the UK. There is a scandalous mis-representation of the illness prevalent which is resulting in ever-greater numbers of people being undiagnosed, mis-diagnosed and under-treated. I know how much background I gave your team, both in my original email and in later follow-up communications, and the situation is not hard to interpret given a little open-minded research.

Your programme did cover the usual ground well but it was only the usual ground - that covered frequently by the tabloids and Breakfast TV.

You did allow Melanie to show that her daughter's illness was missed by many doctors, and how badly it has affected her life. Jane G is good at communicating a real identification and sympathy for her interviewees. Sandra managed to point out that the illness is the most quickly growing vector-borne illness in the northern hemisphere, that PHE figures are an under-estimate, that their help-desk receives other such patient experiences, that there is an urban risk and how to avoid tick bites when out and about. It was a reasonable attempt to cover the basics.

Sadly your item left a lot unsaid and oddly Jane G seemed to be trying to play down the situation. She said that it was an uncommon disease, that risks are "really small", she repeated the misleading idea that it's all about hotspots in the wilds, which is quite wrong and part of the problem, and she failed to allow Melanie to talk about Chloe's treatment abroad. It is really important that people understand that to get proper Lyme treatment it is currently necessary to go abroad, with all the costs that entails. That's what the doctors do....they take their families overseas. She also seemed oddly persistent in trying to tell Melanie that Chloe "IS getting better now". This was so strange. Chloe has been ill for about 4 years and at the time of the interview had done 2 weeks of a 15-18 month treatment unavailable in this country, with no certainty of success. Yes, she has been a little better since Melanie put her on a careful diet including supplements, but this is just preparing the ground. Would it really be acceptable to say "But Chloe is getting better now" to someone who has just started treatment for leukaemia?

So what aspects of Lyme disease were not mentioned by the programme?

\* Doctors are still unaware, dismissive of Lyme because it's "rare" (as mentioned above), continually mis-diagnose rashes, continually mis-use blood tests (as they have done with Michelle Donelan MP), don't understand what the tests mean, and have no idea how to diagnose Lyme without a rash (good question from Jane G but kicked into the long grass and left unanswered) or how to diagnose late Lyme. The guidelines aren't effective but many doctors don't even apply the guidelines. The online RCGP course has been done by only about 2% of doctors, and patients cannot rely on GPs to get this right. Infectious disease consultants are little better informed. Raising awareness amongst the public is no use if the doctors are ignorant.

\* Treatment approved by the guidelines is insufficient to treat Lyme effectively. Jane G said more than once that it is treatable in the early stages to which the answer is "yes, but not by the NHS guideline courses". Studies have shown that 63% people receiving standard treatment in the US (same as here) go on to suffer residual symptoms, some of them life-changing. We are effectively generating yearly cohorts of insufficiently treated people who go on to develop late disease with negative tests.

\* UK tests are inaccurate, believed to be fully accurate by doctors, used inappropriately, and irrelevant for late disease.

\* Tests from established, reputable, accredited foreign labs are not accepted by UK doctors. (The authorities tell us they don't accept results from labs which are not accredited. That is not the same as accepting results from accredited labs, and indeed this doesn't happen.)

\* UK doctors know nothing about the co-infections of Lyme disease, essential for proper treatment. Most UK doctors don't even recognise the names of these coinfections. (Next time you see your doctor just ask out of interest and out of the blue, what s/he knows about babesia, bartonella, mycoplasma, anaplasma or ehrlichia.)

\* Reporting of Lyme disease numbers is illogical and incomplete, so we have no evidence of how serious this is.

\* Most people who get effective treatment for Lyme do so by going abroad. This is grossly unfair and inexcusable in modern Britain.

\* Congenital transmission was not mentioned.

\* Sexual transmission was not mentioned.

\* Contamination of the blood supply was not mentioned.

The last three are both controversial and vitally important. Surely that means they are worthy of comment? There is scientific evidence which supports concern in all these three areas but PHE and others will not consider it. This was, you remember, the case with AIDS and variant CJD. Syphilis, you will be aware, which is a “dumb cousin” of the Lyme bacterium, is transmitted in all these ways.

I have also to say that I was disappointed that you asked LDA to take part. A very large part of the Lyme patient community has no faith in LDA to represent us, they have no mandate to do so and do not engage in consultation with UK Lyme patients in general. They don't have "members" so there is no way to calculate the support they enjoy. They have acquired the confidence of government and PHE, a dubious qualification when patients and international Lyme experts see these bodies as standing in the way of good policy and treatment, and present themselves as the UK authority on Lyme. They are no doubt well-meaning but there is no justification for treating them either as experts or as patient representatives. I gave you very many examples of experts who would have been able to speak to you, access to several other knowledgeable patients and Caudwell-Lyme had their CEO ready to be interviewed.

As an indication of how acute this problem is, I notice that in the 9 months since I first wrote to WH, our support group has grown by about 1800 members. That's 1800 individuals who think that Lyme is affecting them or someone they care about, who are worried enough about their disease to search online to find support. This must be the tip of the iceberg as surely only a small proportion of the real numbers will a) be on Facebook b) realise that Lyme is their problem c) search for a FB support group, find ours, and join it.

I suspect that Woman's Hour will protest that there was not enough time to cover everything, but you did a whole programme on insomnia (which incidentally is a symptom of Lyme disease) recently. As an example of how pervasive this illness is and how relevant it may be to many people, one of your interviewees on chronic illness on 21st Jan, Jules, had a suite of symptoms very typical of undiagnosed Lyme - fibromyalgia, EDS, autonomic dysfunction and Arthritis. Were she diagnosed she might be able to get treatment to improve her condition.

I'm not presented with many alternatives to explain why the BBC refuses to cover the difficult aspects of Lyme (basically the list of issues above). I find it hard to believe that a group of intelligent women like yourselves can look at the evidence that exists about Lyme and not see a deep, interesting, relevant and socially important story, affecting many thousands of UK women. It is difficult not to feel that there is a blackout on the subject.

Sadly whatever the reason, it remains the case that for hundreds of children this year who are bitten by infected ticks only a very few will successfully overcome the hurdles of the tick being seen, a rash occurring and being taken to a doctor who knows what to do. Even for them, the treatment will be too short to guarantee recovery. There is no alternative for parents of infected children other than taking them abroad or turning to alternative practitioners. It's possible for infected adults to treat themselves in various ways, but parents have to leave their children to whatever the NHS deems appropriate.

I realise you felt you were doing a good thing with the piece on Lyme, and as far as it went, it was a good thing. But your listeners only heard a tenth of what they needed to hear. Sadly, I believe that we need to get to a critical mass of lives destroyed or enough influential people to have partners or children destroyed by it, before anything is done.

I would be very interested to know if the item generated any interest amongst your listeners. I'd like to close with a statement from one of the co-founders of LDUK which can be found [here](#). When she says "we lost" she means that the lady committed suicide.

***Louise Alban***

*(Slightly edited for privacy and clarity)*

To read more letters, click [here](#).