

Dear editors,

I listened with interest to your piece about Lyme disease yesterday and whilst it was good to hear it actually covered on the BBC it all seemed very superficial to a long time Lyme sufferer like me.

Time and time again, short newsy pieces with some human interest are covered by broadcasters and the press however it seems that no one will actually cover the real issue here, the systematic denial by government and medics that there is an epidemic of biblical proportions which is causing people to be severely disabled and which largely goes untreated. The only people who recover from this are those who spend large amounts of money, tens of thousands of pounds, obtaining treatment abroad.

I was bitten twenty five years ago in my own garden in Devon, had the characteristic rash, presented to my GP who then duly ignored it. Fast forward twenty five years, I am largely housebound, have severe mobility problems, have numerous spurious diagnosis obtained on the merry go round of NHS clinics and specialists whilst in practice my health is still deteriorating. I lost a promising career in industry, my house, most of my friends, life as I knew it and any meaningful sort of existence.

In 2007 fifteen years after the bite and rash I saw a picture of my rash on the Internet. After researching it I discovered I may have Lyme. Samples were sent to the USA and in due course I received a positive test result. The NHS ignored this and failed to treat me, all the while spending more and more money sending me round the merry go round of consultants in the quest for different diagnosis yet again. They ignored the simple diagnosis I already had. I used my life savings to obtain private treatment and did significantly improve for a few years, however after further bites in 2014, I have relapsed. After 25 years of being unable to work and spending my savings the first time I can not afford further treatment. I therefore face a bleak future for the rest of my life.

I fail to understand why there is a such a cover up, even the Lyme Disease Association who's representative you had on your program are complicit in this, repeating long held beliefs and half truths and failing to engage fully with the patient community. They work hand in glove with PHE and the NHS and ignore the wealth of peer reviewed research available in the rest of the world which points the way to further knowledge and successful treatment.

The charity Caudwell Lyme Disease has recently reported the results of their patient survey into the effects of Lyme disease on 500 people. This would make a good starting point for further

analysis of the situation yet the press have studiously avoided it.

I cannot help but believe there is a cover up of monumental proportions over this disease and that the BBC are following some sort of government agenda in suppressing the real nature of the problem. Only when this matter is blown wide open, relevant treatment made available and knowledge from world wide experts shared here, will patients make any significant progress. It's probably too late for me, the ravages of the disease have had too many effects but I would like to think that others will not suffer in the way I have for over a quarter of a century.

Jacinth Mathews

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