

Dear Woman's Hour,

I'm English living in Hamburg. Thank you for raising awareness about Lyme Disease today.

In 2004, after having symptoms for 2 years, I was told by two doctors I had borrelia in my blood but not that it was anything to worry about. The symptoms (unexplained depression when life was good and an even more inexplicable, uncharacteristic, frightening inner rage, a skin rash) continued to increase in severity for the next 3 years during which I went through a wide range of antidepressants, all to no effect. In 2007, through a chance conversation, I heard about Lyme Disease and remembered I had once been told I had borrelia in my blood. I then told the doctors who then dismissed this and still insisted it was psychological, even though by that time I had developed severe head pains, head pressure, severe cognitive deficits, difficulty understanding language whether English or German, paralysis and a major fit. The blood tests came back as positive but the psychologists dismissed them again as they didn't fully tally with the prevailing standard guidelines. It's now well known these are out of line with current research. I tried to come back to the UK and was aghast to discover there was no provision on the NHS for Lyme Disease.

In April 2007, after running the Paris marathon (I was a marathon runner and used to go training in the woods), the symptoms increased dramatically and I had major difficulties in perceiving the world, my brain felt like a stone, thoughts came in fragments and I struggled to form sentences. Still the doctors didn't believe me and placed me, rather brutally, in a psychiatric hospital (!).

By that time and by reading up on the subject, I was thinking that it might possibly be neuroborreliosis. I called the patient organisation in Canada, CANLyme, who said it sounded like neuroborreliosis. I managed to call ILADS, a Lyme advocacy organisation in the States, and ask for doctors in northern Germany. I called one in Berlin from the psychiatric hospital and fortunately he believed me, saying it often happened. I discharged myself and went to Scotland for a week to be with friends and experience some humanity, but the symptoms were increasing. I responded positively to the antibiotics the doctor in Berlin gave me but they weren't enough and I was falling into a coma-like state with my thoughts becoming even more fragmented, the brain pressure intensifying, and my muscles twitching. It was becoming increasingly difficult to perceive the world. I found the website EUALB and persuaded the Berlin doctor to administer IV ceftriaxone. Immediately after the drip I noticed a difference.

With what felt like brain function of 20%, massive burning head pains and brain pressure, and by a

stroke of luck, I found a Lyme doctor in Hamburg.

I contacted his surgery but was told there was a 2 month waiting list. I said I would be in a coma by that time but they refused to bring the appointment forward. A week later I rang again and was refused again. With help I managed to get my GP to call the practice and I was taken as an emergency patient. When I finally sat before the Lyme doctor, trying to speak, he said calmly 'you haven't told me anything I've not heard before' and immediately put up an IV drip of ceftriaxone, an antibiotic.

I thought I had an unusual story worthy of Der Spiegel. Then I spoke with other patients at the surgery and my story is pretty standard: not being believed, being told it's psychiatric (even to children), and doctors without the knowledge to treat.

The IV ceftriaxone treatment combined with other antibiotics continued for 3 years. Then I said we should stop because I felt fine.

Three months after stopping, the Lyme Disease came back with a vengeance throughout my body. I felt as if my flesh was wired to the mains. I accepted my fate and said as long as it's not in my brain again, I'll take the treatment again. A week later it returned like a thick fog into my brain. There followed a further year and a half years of weekly drips, including a bout of clostridium difficil.

I then had a year and a half of reasonable health but in September 2014 it returned. I haven't been able to work since then and as a result have lost my (brilliant) job as a technical translator.

Last October, I again had paralysis and horrifically burning skin. I thought I'd try again at the hospital. They again, bizarrely, put me in psychiatry as they looked in the archives, saw what the previous doctors did and copied this. I said it was a wrong diagnosis and I had years of treatment for Lyme behind me. They ignored me and dismissed all blood results. Three doctors - my GP, the renowned laboratory doctor Dr Armin Schwarzbach of ArminLabs who specialises in tick-borne illnesses, and a Lyme doctor I'd seen in Berlin - rang the hospital but they ignored them. To depart from the diagnosis from 2007 would mean to admit they were wrong. Dr Schwarzbach later wrote to me in a mail that from his conversation the ward psychiatrist had little idea of viruses and bacteria and their effect on the human body. I discharged myself after a week still in horrific burning pain. My squirming around unable to sit still on the chair due to pain was described in the discharge report as 'scurrilous behaviour'. It really is an abuse of human rights. My friends are

horrified with how I've been treated. And still I can't return to the UK due to the absence of specialists for late-stage Lyme Disease.

My very humane and committed doctor in Hamburg went private as the pressure from the insurance companies to keep to their very low budgets for a multi-system illness was too great and he was heavily fined for going over budget. Although I pay health insurance, I cannot use it as treatment for late-stage Lyme lies outside what's considered standard medicine, so have to pay all my health costs for this illness myself. The costs are huge, e.g. last week I spent over €4000 for apheresis (blood washing) and hyperthermia down south.

I cannot work, my life savings are dwindling and will soon be gone, and I am still in excruciating pain with severe cognitive deficits daily. It's truly kafkaesque. I cannot see how this can continue for much longer, either physically or financially. Being the practical and solution-oriented type, I've joined Dignitas, which I find a very strange fact indeed for someone so adventurous, athletic, and life-loving. It's not about life and death, though, it's about getting out of pain.

I am by no means an isolated case. There are very, very many such sufferers in the UK, Germany, Spain, France - recently Matthias Lacoste in France was on hunger strike for the right to treatment - and many other countries with not dissimilar stories. I have heard countless. Earlier this year there were awareness-raising demonstrations in Hamburg, London and other cities about the situation. It's not a rare disease, it's a real problem and on the increase.

Thank you for the item and I hope you will continue to spread awareness and highlight patients' plight so that change can be effected and so that I have the choice of returning to the UK.

Kindest regards,

Kathryn

Hamburg

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