

LYME DISEASE ON THE NHS

CAUDWELL LYME DISEASE CHARITY

PATIENT SURVEY RESULTS 2016

Q23: QUALITY OF LIFE

HOW HAS YOUR QUALITY OF LIFE CHANGED AS A RESULT OF CATCHING LYME DISEASE?

434 TEXT RESPONSES WERE RECEIVED.

THEY ARE REPRODUCED HERE IN UNEDITED FORM.

It has totally destroyed my life and that of my family.

I am unable to function normally in any way and sleep all the time, even during meals. Prior to being bitten I was enjoying a full, very active life and motorcycling around the USA for 3 weeks with my wife (who has to type this as I am unable to). Within a few weeks of returning home to the UK I became extremely sleepy and was very confused and disorientated.

In the last 12 years I have been diagnosed with Narcolepsy and a multitude of psychological illnesses and have even been told by a Neurologist that my symptoms were 'nonsense'. I have no social life and I cannot even cope with visits from my grandchildren. I cannot walk more than a few yards without collapsing when before I was bitten I used to run 2 miles every lunchtime at work.

My wife is my carer and has to help me to eat my food sometimes when I am too weak to hold the fork and she has to deal with all my medications/ appointments and daily routine as my memory is so bad.

We would not allow our pets to suffer this way yet nobody takes us seriously when we ask for help.

Thank you so much for allowing us all to have a voice

For 18 months I was misdiagnosed as having CFS/ME. I was previously an athletic person that would run triathlons at Olympic distance. Lyme disease has affected my whole life. I at the moment am left unable to work. Emotionally it's had an impact on not just me but my family husband and two small children aged 10 and 8. I have no quality of life and struggle with tasks like housework and making my children's dinner. Lyme disease took 6 months to properly get a hold of me physically and then most days were spent in bed or on a sofa in my pyjamas. I was seriously ill and in pain for a good year of it with numerous symptoms.

I was very distressed. 2 months before my diagnosis I was talking about a wheelchair as my legs were so bad. I was very close as I could hardly walk. Obviously I haven't had a social life at all. It's more like an existence you battle on for the sake of your family and loved ones. It's a horrendous illness/disease.

I am constantly tired and dizzy. I am unable to work full time and frequently have to spend entire days in bed. My social life has dwindled away and I spend significant amounts of time and money on treatments (including nutritional supplements) privately as the NHS were not helpful, luckily I am able to afford this. The emotional impact has been significant as at one point I really started to believe (after having been told so many times) that the problem was in my head. Although diagnosis was a relief, I feel sad at the many years of my life that have been lost trying to find out what was wrong. I have just started treatment and even though I know it will be a long process, I am hopeful for the future.

My life is extremely limited, I am unable to walk far and need the aid of a stick, I am in constant pain, in every joint and muscle. I have trouble sleeping and am constantly fatigued. My social life is non-existent and my leisure activities are kept to a minimum as I save all my energy for my work as a Finance manager in Local Government, fortunately I love my job but I don't know how long I can manage to carry on with it.

Let go from full time work due to health issues. No social life at all due to fatigue and a confused state of mind. Unable to exercise or go out with friends and family.

I am 10 and I can't do sports, and I can't keep up with my friends when they play outside. My legs hurt pretty much all the time. Sometimes when they run around out of doors I just sit and play computer games or watch TV by myself and then sometimes that makes me cry when I get home afterwards.

I often get headaches, or else my eyes and brain go funny and I can't do my schoolwork. I find it so hard doing maths, I am good at it sometimes like I used to be but other times I am so stupid I want to punch myself in my stupid brain. And I hate myself.

When I was 8 I was very depressed and I wanted to be dead. I told my mummy I thought it would be better if I killed myself. I can't remember what it was like when I was smaller than that except I was in hospital a lot and I don't even want to talk about that.

I do not have enough energy to work. I have a university degree and am bilingual. I used to work full time in the city in investment banking. At 38 I got Epstein Barr virus which exacerbated my Lyme disease. I ended up working part time as a shop assistant and spending all my free time lying down shattered and in bad pain. My house was dirty and I was depressed. I later had a child who is now three. I teach English for one hour a week and can manage the minimum around the house. I can't imagine how I could possibly work in my old career, I am too fatigued, vague and I can no longer focus or remember words mid sentence. My numeracy and spelling are not the same. It takes days to weeks to recover from days out. I do no exercise because I simply can't recover. I limp frequently and cannot use a keyboard regularly. I sleep badly. I can't wear formal footwear because of my hip pain. I am not the person I used to be. I depend heavily on my husband. I earn 2.4% of my former salary. I can't see this

changing. I don't have the focus or energy to set something up for myself to earn from home, much as I would like to.

What life, I lost my degree, career, family, friends. I'm housebound except for good days when I take handfuls of vitamins and b12 injections daily. Sometimes I just want to give up myself.

I had a very active lifestyle with four children and a husband. I can no longer participate in any activity other than a short slow walk. I spend endless days in bed with flu like symptoms, joint and head pain. I am sensitive to light and sound which makes socializing uncomfortable and triggers panic attacks. I used to be a happy carefree person. I'm now very slow, frustrated and sad most of the time.

My kids and husband suffer and want their wife and mother back.

I became ill in 2009 worked full time, lost job in 2011 not worked since, mostly housebound from 2011-2014 but have improved the last 12 months through private treatment.

Lyme disease has changed me as a person, I have no faith in the NHS, they made me feel a fraud, I now avoid NHS at all costs! They totally humiliated me, I had severe symptoms but was told 'my brain is wired up wrong, it thinks your still unwell, but your not, and that I need rewiring' this was the CFS/ME clinic CBT. Also prescribed Modafinil.

My GP told me I didn't have Lyme as not in the area, and that I would be more ill if I had Lyme, at this time I was spending 18 hrs sleeping, I couldn't walk due to severe pain in my back and hips, I had severe migraines every day, I couldn't put a sentence together as forgot words, I had palpitations, couldn't swallow, night sweats, the fatigue is like someone pulled the plug.

To top it off my private GP can no longer practice as being investigated by the GMC.

I had no social life, friends/family didn't believe me, so even now lost confidence in me and people. Basically it ruined my life.

Going through the 50 pages to claim benefits and the humiliation is disgusting.

I cannot work, I cannot exercise, I cannot walk my dogs or make love with my husband, I cannot spend quality time with my children and I have to use a wheelchair to leave the house. I have lost most of my

My whole life has been turned upside down. I have a husband and two beautiful children. My illness has affected my relationship with my husband, but we are trying as a family to work things out. I feel so guilty that I cannot take my children to the park or even have fun time with them as I am in excruciating pain. My mindset has been affected me heavily due to this illness and feel a complete emotional wreck. My self esteem has gone as I just want to be in bed all day and prefer to be left alone.

Psychologically I feel my children are suffering too and finding it hard to cope with as mummy is always asleep. I have given up work because I could not take the pain and literally felt like a zombie all day. I sometimes lose the will to live and feel so depressed by the pain and the other effects of Lyme.

I have no social life (except online), my boyfriend cares for me, I cannot work, and cannot go to university as I'd always planned. I rely on other people for the simplest of things; cooking, shopping, washing my hair, cleaning, leaving the house (I need a wheelchair) etc. I'm not living, I'm existing; this isn't much of a life

I can't be a good mother and. Wife... Always sick. Feel like I am dying every day. Pain and anxiety

I have zero quality of life. This is a living death. I am in agony 24/7, month after month, year after year, decade after decade. I am 95% bedridden and 5% housebound. I live in

a darkened room and this is my prison. It's bad enough being ill, but what really adds insult to injury is being dismissed and ignored and treated like a turd by the medical profession and politicians. WAKE UP. Lyme and related disease is destroying lives on an industrial scale and nobody cares.

I am a 25 year old Nutritionist, bedbound with chronic fatigue and an array of Lyme disease symptoms tachycardia, palpitations, muscle spasms, sleep apnea, air hunger, depression, anxiety, paraesthesia, lymphatic swelling. One night my breathing symptoms became so severe that I was rushed to A&E, and it was there that I finally received my diagnosis of Lyme disease. Over the past few years I have received devastating misdiagnoses including bipolar II, panic disorder, and interstitial cystitis. This disease has crushed me. I am exhausted. Worn down. A shadow of my former self and a thousand miles away from the person I believed I'd be at 25. I spent my 25th birthday in hospital. I have lost my confidence. I am back at home living with my parents, unable to work, fearful of my future, and grieving the loss of my life, my career, my mind, my body, my happiness. I battled with this nameless disease for years before diagnosis, knowing that I was not well and trying everything under the sun to restore my health nutrition, exercise, alternative therapies, meditation. In my mind, this proves the sheer complexity and severity of Lyme disease: it requires serious antibiotic treatment, it requires investigation in to coinfections, it requires a wellformulated treatment protocol, and referrals to relevant specialists such as neurologists and cardiologists. Selfhelp is not enough. But sadly, for the majority of Lyme patients, selfhelp is all there is. I am lucky to have parents who are financially supporting my journey to recovery. Without them, I would not have been able to cope. On bad days I am bedbound and suicidal, my body might forget to breathe, I might be crippled with neck pain, or unable to think straight and form a sentence. On good days I might manage a short walk outside, a brief visit from a friend, or time to continue my research in to Lyme, reply to emails, or fill out paperwork. This is my life. If I was not me, I would not believe it. And this is one of the problems of the disease: many do not

believe it, and many do not understand it. It is a gross injustice that the NHS is not allowing those sick with this disease to get better.

I had Lymes Test done on NHS and at Breakspear medical group in 2015 the test was called Lyme multi peptide 1gG ELISA Assay and Lyme multi peptide 1gM ELISA Assay and Lyme Antibodies peptides were considered Equivocal and Lyme disease by Western blot came back negative. I was told by Breakspear medical group I had no active Lyme disease. I am still in lots of pain and went to see a Bioresonance Practitioner who said I have Lymes. My life has fell to pieces I have no social life no family responses. My relationship is breaking down and I now need to know for certain if I have Lyme Disease as I am fed up with being pushed from pillar to post by NHS and Private Consultants. No one is taking full responsibility for me to get better. The Doctors don't know where to send me next although they have arranged many many appointments they informed me I'm a difficult case and must accept I have Fibromyalgia and told to get on with it. I have paid out a fortune to see Private Consultants .I just feel I don't want to go on any more.

No more long term goals, less vitality

Unable to drive any distance greater than about 15 miles, which means I can no longer take my dogs to dog shows or other events, or visit friends or relatives outside of my immediate area

Unable to move to France (planned for last autumn)

Unable to walk with my dogs in local countryside

When I was Younger I was unstoppable, had heaps of manic energy and never slept, If I wasn't working I would be off on a horse or bicycle or to see friends. Now... I have withdrawn from society, live alone, am often unable to leave my bed. I get a maximum of 2 good days per month during which I exhaust myself further catching up. I have lost

countless jobs due to ill health/unreliability therefor unable to persue a career despite a private education.I have a huge debt hanging over me which I am paying back despite the fact that I vehemently disagree with the amount of £19.5k, I even enlisted help from 2 charities but to no avail. I was badly bullied as a child for bedwetting, obesity and having a horribly red face which I now know was the inflammation caused by the Borrelia. I feel very alone and misunderstood, struggle with relationships and have never married or had children. I have always felt different to other people somehow as my peculiar symptoms began at age 5 when I had an undiagnosed illness; fever, headpain and a circular rash. For me Lyme has had an impact every possible avenue of my life.

I was bitten at DisneyLand Paris in June 2013 on a family holiday. I had the classic bullseye rash all over my body and prescribed one week's worth of antibiotics then I never gave it a second thought. Initially I had severe flu like symptoms which left me bed bound most weekends at the time my daughter was only 4 years old. I found it incredibly difficult to lift my legs and so my husband had to assist me up the stairs and into bed. Symptoms became more severe and I had a random range of anxieties that developed including a fear of falling through floorsI slept on the lounge floor and I was afraid to shower incase the floor gave way this had a huge impact on mine and family's life. I visited the GP regularly during this time and was told I was suffering from work related stress I was also referred to a psychologist. I am a lecturer in a busy city centre Further Education college and because I thought it was my job making me poorly I was more determined to not take time off. It was the most difficult and stressful time. I thought I was going crazy I was fatigued, run down, my face drooped on one side and my brain didn't feel like it belonged to me. My anxieties added to my tiredness untill I eventually I broke down (I was walking over a bridge contemplating suicide on the way to collect my daughter from school and felt my family would be better off without me and that they had had enough of my ailments and struggles). My husband googled my symptoms and realised I had Lyme Disease. Eventually I took some time off work and

my blood was sent for testing at this point my bites had reappeared and so was prescribed a further 2 weeks of Doxycycline I began to feel better for a couple of weeks but then slowly started with aching joints difficulty walking up the stairs on an evening brain fog. The GP said it would be highly unlikely that I would have Lyme Disease especially from Disneyland and especially if I hadn't seen a tick! I received a positive result and given 4 weeks Doxycycline in 2014. I felt better again for a few weeks but then slowly my aching joints and brain fog returned. I reduced my fulltime teaching hours to parttime as by the end of the working week I can't function or move. My daughter is now 7 and I also have a 1 year old son. I was reluctant to get pregnant as there is an uncertainty about Lyme being passed on but I had been given the all clear from the Infectious Disease Dept in 2014 so I waited another year to be certain. My symptoms seemed to subside during my pregnancy but as soon as I gave birth I have struggled to walk properly as I have a searing pain in right hip, I had my gall bladder removed due to violent stomach attacks apparently my liver results were abnormal from 2013 when I was bitten. Even reaching down to pick my son up hurts and luckily my husband runs around after the children on an evening but I don't want to live like this. I have visited the GP a ridiculous amount of times so much so I am afraid to go my current symptoms are vitamin d deficient, aching joints, searing pain in hands, hands curling in, cold feet and hands, dizzy spells on standing, unable to straighten back on standing, difficulty walking up the stairs on an evening, forgetfulness and struggle to find my words which has become more apparent whilst I am teaching my students.

My symptoms seem to worsen on a 34 week cycle. When I have a lapse I am physically and mentally fatigued and sore my body feels bruised and shaky. The most frustrating thing is that even though I tested positive for *Borrelia Burgdorferi* my ongoing symptoms are not linked to me having Lyme Disease and the NHS continue to waste money testing my blood for illnesses I do not have. So when I get the all clear I have to phone the doctors again and make another appointment. I think they think I have been treated and that is it so why have I never felt well since being bitten? I rarely visited the doctors and now I have to go regularly and relay all my symptoms to yet another GP.

I had moderate severe ME before Lyme. Lyme had made me very severe hardly leaving bed, let alone the house. I can't make myself food, tidy up, sit upright for long, walk, I wash every few days because it's too exhausting. It's humiliating and we get no help. Had to fight for PIP which I've just been awarded but feel too unwell to start employing people.

Every patient in the UK that has Seronegative Lyme has been abused and treated like garbage. Your doctors have abused us not just once or twice but continually for decades. I don't know of many seronegative Lyme patients that like the NHS you treat us like dirt. We suffer immensely not just with the disease itself but from the so-called medical profession. We are told we are wasting your time, we are laughed at by your consultants, we are lied to and refused treatment. My dog gets better treatment at the vets than I get from the NHS.

Since diagnosis my life has changed dramatically. I feel I have aged 10 years in 18 months. Mobility problems due to back and hip pain, chronic fatigue, sleep deprivation due to legs going into spasms and jumping all night. Rain fog where my mind goes blank, getting words mixed up, severe migraines. Currently working full time but finding it more and more difficult, but cannot give it up for financial reasons. Weekends spent in bed.

Lack of joy and interest in life career development, intimate relations, social life Anxiety, Depression, Insomnia and sometimes suicidal thoughts. Cannot exercise or be active due to post exertional malaise. Loss of freedom and enjoyment. Deep grief. Feels like Groundhog Day!

I have lost my job and lost many possible incomes. I could not develop my professional career or my personal life. I am stuck in my mum house because I do not have enough cash to survive by myself.

I have managed my 'fibromyalgia' with private health care. Massage, tolerable exercise, acupuncture and sacrocranial treatments. Only had Bulls Eye rash in July 2015. I went to see Breakspear Clinic in Hemel Hempstead as had four different skin conditions and chronic food intolerances. The LDI they use has been effective. Now under care of Jemsek Clinic in Washington, USA for Lyme treatment using antibiotics to treat symptoms, not more blood tests. Seems to be working although early days. Consider need up to two years of treatment before I am free of Lyme and coinfections.

It has completely changed my life I had to stop working when I became ill a year ago I find it really hard to go out and meet friend. Becuase it tires me out.

YES

GET TIRED VERY EASILY. CANT DRINK AT ALL

My marriage has broken down due to Lyme disease, my quality of life has deteriorated severely and rapidly, my mobility issues have worsened

Completely ruined. I struggle to get to work. I lost my previous job because of Lyme, and I was unemployed for 18 months. I struggle with everything. I barely exercise, find it hard to walk. I would like to change jobs but travel is a major problem for me. Three relationships have ended because of my illness. I have basically lost around 12 years of my life, and it still continues. I had so many plans for travel and working abroad, but I am not able to do these.

It has ruined my life

Job lost due to debilitating symptoms. As a young family with two toddlers struggle on monthly basis with no financial support from anyone. Had good prosperous career in oil and gas and worked very hard and was providing for my family and never claim any money ever.

Family stress and worry throughout family I.e wife parents grandparents sibling leading to there own health being effected.

Friends find it difficult to understand as I get 'you look Ok'

I have been brought up to work hard and do right. Never taken drugs, never drink (gym goer 5days a week prior to Lyme) always respected !y body and though I was protecting my self by doing the right things. Never visited GPs and life was comfortable and content. Fantastic family I am blessed. Got married saved to have children all was perfect. Now I feel is a struggle and a challenge and being someone who has always done right seeing people who self inflict illness often claiming all there money and housing being treated for drug related diseases or sexual diseases Upsets me as I didn't ask or take a risk and get this. There is no support for people with a bacterial infection that is systematic Why?

My knees have been affected and there is no improvement with taking methotrazate. The consultant suggested taking a higher dosage, but I cannot imagine it will help. It is pretty depressing that the symtons are getting worse.

Lyme disease has not yet killed me but it's taken my life!

In the 20 yrs following my Lyme Disease diagnosis, the following has occurred...
I lost my job in banking as I was too sick to work. I can no longer drive a car. I cannot walk very far. I have lost friends and I have no social life. I am mostly house/bed bound. Cannot enjoy holidays. I wish I was dead.

I have lost friends, gone into huge debt, been bedridden and lost my quality of life.

Utterly disabled, cannot work, start a family etc. No support, rediculously poor diagnostic tests and no treatment!!

I lost my job due to taking too many sick days, I have no social life as cannot go out due to pain and. feeling nausea all the time

It's ruined my life. I couldn't pursue the career I wanted, all my money has gone towards treatments, my fiancé has left me (who I'm worried has it too), my kids emotions are all over the place, friends have disappeared one by one. I feel like I'm still me but I'm trapped inside an alien body and nobody knows who I am anymore. I look good and strong and positive on the outside because I have to be but it's the scariest place ever been and I want out! I want my life back!

I have been stuck in icu for nearly 2 years so I don't have a life

We've lost our home and I'm now being investigated for benefit fraud

It takes all my effort to put one foot in front of the other . Constant joint pain and chronic fatigue. Everyday it takes all my energy to just get up and dressed . I feel my children have been robbed of their mother . I was misdiagnosed 23 years ago. It's difficult not to feel angry about this as ill health has plagued pretty much the whole of my adult life

Yes I suffer from tinnitus and joint problems.

I was a senior lab technician, martial artist, rower, dancer and competed in crossbow, taking my 5th and 6th science based degrees online.

I am now befbound, in constant pain, cannot walk, cannot read, brain fog, tremors, cannot wash or dress myself. I am exhausted all the time and have together someone else to read and write for me. It is joking of life. Just inescapable constant pain

My life was taking away from me. I used to be athlete, active mum, and psychotherapist. The doctors left me dead misdiagnose for ALS. Luckily I seeked out test from Igenex. I'm homebound. I cannot speak. I have trouble writing. I have Progressive Apraxia of Speech caused by Lyme.

Stopped my progression on an msc program.

Needed 3 months off work until I started treatment with Antibiotics.

Could not drive due to memory and anxiety problems

Could not remember my daughter being born or even what month.

Could not walk around in the park with my 2 year old too much fatigue.

Difficulty with mood swings and rage.

Problems/ hypersensitivity to noise and light making me very aggravated.

Generally very difficult to live a normal life and relate to my children

It's stolen my life, I have no choice but to pay privately to get it back for me and my family, my choice is simple fund your life or loose it forever.

Devastating to both myself and my husband. Very little support or understanding.

I no longer function as I used to. I am tired all the time, have body ticks, heart palpitations, pains, sweats, hearing is very sensitive and the same for smell. Lots of other minor symptoms too.

Off work 6 months. Having to consider early retirement soon as can't continue

Unable to do sports I did prior to Lyme

Don't socialise much as its difficult in those environments but also I no longer drink alcohol & diet is restricted which makes these occasions difficult

It has left me unsure of whether I actually have MS now. I struggle to still work full time, but feel I have to to save money for treatment should my symptoms get worse as there is no guarantee that the NHS would help me. At least with MS I had reassurance that I would receive help from the NHS. I also have BUPA cover, but they won't help either. I've been referred to a rheumatologist, but he snubs my diagnosis of Lyme from Germany, even though I've been seeing him for 3 years now with no diagnosis from him for my arthritic symptoms.

I was off work for 6 months, the Brain MRI (when correctly read by the neurologist) and lumber puncture revealed that the Lyme had caused meningitis and I was in agonising, stabbing pains in my back. My chest and upper back/ shoulder blades were numb to touch, my fingers had constant pins and needles. I lost 3 Sones in weight and couldn't even get out of bed by myself. I never slept for 3 months with the pain until I was prescribed Butans patches and Amytryptaline. I now have Tinnitus, my chest is still numb, I have headaches and an irregular heartbeat. Lyme has also affected my bladder but this seems to be recovering after the antibiotics

Because of my severely reduced energy levels, I am unable to be as active as I was in the past. Getting up in the morning, socialising, gardening, etc. etc. all require a great effort and also lease me very exhausted.

I can no longer work full time. Been part time 10 years. I consider that I do no live I exist juggling pain, fatigue and trying to keep myself sane and positive.

Yes every aspect from daily routine trying to keep my house clean, be a mother to a 2 and 4 year old, try to work because I am a dentist and went to school for 8 years and

still have to pay back my student loans, this Disease is life altering its not just an antibiotic it will fix you, it's complex involves antibiotics, supplements, eating healthy, alternative acupuncture etc to help this Disease and everything is out of pocket! I had to go to a Lyme literate doctor because no doctors in America know how to treat this Disease nor do they want to have anything to do with it, the labs are inaccurate I was initially negative from my PCP than went to my LLD and he used igenex ISPOT and Elisa peptide my results were positive

I have no life . I became ill aged 7 after moving to the country . I woke paralysed . I developed a stutter , fatigue , leg pain . It took weeks to learn to walk again I was told I had a virus . I never fully recovered . By age 15 I left school too ill to continue . I was diagnosed with ME . Wheelchair bound . Bed bound , spoon fed . Aged 36 I finally find out about Lyme disease . I have it . Devastated , I've lost my whole chance at life . A childhood . Teenage years . My education and I was a star pupil . A Career , a marriage and a family . I have never ever had a job . I feel inept . I'm scared how can one be so ill yet there is no help ?

Ended career as academic scientist.

Is an obstacle to being an effective parent.

Left me housebound/bedbound

I got bitten by a tick in 2010, the tick had been inbedded in my back for 3 days when I went to Halifax A&E where a nurse had a pull at it with tweezers it wouldnt let go so she got a Dr who pulled the tick with tweezers he said does that hurt i said no, he then released the tick and got a skalpull and pulled it again with tweezers it still wouldnt let go so he shaved it off me, leaving part of the tick in me, I was back in A&E 2 weeks latter and admitted for about 10 days where they did all kinds of tests but couldnt find anything wrong, 18 month latter i went privet and got my blood sent to USA came back positive iv had two three month of antibiotics plus other supplyments, costing me

about £10,000.00, before i got bitten by the tick I had savings, good health, good looks, a good business, a house with 2 acres of land, a partner, 2 cars, 2 motor bikes, a good life. Now I have no savings, bad health, I look terrible, No business unable to work, no partner, no house, no land, no cars, no bikes unable to drive due to stress, I have a very poor life style now i am ill ever day. I lost it all to Lyme due to the Dr at Halifax A&E not knowing anything about Lyme. My GP didnt know anything about Lyme but tried to help so I went private. My vet knows a lot about Lyme disease but the NHS knows nothing???

I sold my house, funded my own treatment, became selfemployed to manage my own hours around the pain and fatigue, but ultimately even the steroids couldn't keep me from becoming bedbound. I don't remember my sons final years at high school, relied on family to care for them whilst I spent four months receiving IV abx treatment at a private clinic. Struggled after with different abx regimes for another two years, unable at times to withstand the herx's with a beaten, damaged immune response.

I don't have a social life, I've become a prisoner existing in my own home, well that is my landlords home. Plus side is 15 years later, I'm not in constant agony with my neck and brain in a vice, and I've regained my sight. Oh and my 16 yr old son met a girl whilst I was away at 4 month private clinic. When I returned home we learned she was pregnant. That was seven years ago now; luckily happy ending, they're still together, both at "uni" and now have two beautiful daughters. Life after Lime? Just

I was a track and field athlete and also training at medical school this all had to stop. I have no money and am totally reliant on my mother, and have no job or social life.

My life feels like a husk; I am a person without life. I have no job, no social life, can no longer drive, find talking difficult, can no longer read. My days are spent always doing the same thing; just getting through the day with the least physical stress and maintaining my health the best I can. My family alternate between tolerance and

frustration/anger with my lack of abilities. The financial burden of any private treatment falls to my husband who must not only work long hours but also see to all household management and care of children. When I do make practical contribution towards family life, everything must be checked because of my history of creating chaos with my mistakes. My children have had to take on adult responsibilities long before they should have. I feel like I am the child in our family.

completely changed

My university studies are affected as I cannot get extended time for my exams even though my right arm has lost some of the function and that makes it difficult to write for a long period of time

I no longer have a life the majority of my time is spent bed bound owing to numerous debilitating symptoms. I am unable to work. I don't have a social life and i have also lost some close family members owing to this horrible disease. I have tried a few treatments privately unfortunately none worked and owing to my financial situation i could not afford to keep the costs up.

Initially I had a variety of symptoms including cognitive impairment, heart disturbances, multiple joint pains, and visual disturbances. These impacted on my ability to work and generally caused mild depression. After discovering my treatment (see Q21) my health improved over a period of several months to a point where Lyme now has minimal impact. I just have to spend roughly £20£30 per month to maintain my treatment.

I played football at an elite level since the age of 7 years old. I am now 17. I could have played for England. All I want to do is my A levels to become and doctor and play football. It has taken over my life since 13 years old being bit whilst on holiday at a

Eurocamp in Italy surrounded by wild deer. 10 weeks before NHS agreed to give me a weeks IV antibiotics then pushed for another week as was improving symptoms. Said it was in my head. The doctor would not entertain it could be lyme disease.

Having Lyme Disease has completely devastated my life, I had to cut from five days a week working as an NHS Phlebotomist to only working three mornings, and now after the latest 3 month relapse I am going to have to cut to two mornings, financially we are so much worse off, we cant move house, I cant do the job I love, I struggle to look after my grandchildren, I cant eat what I would like to, and we dont socialize because I cant tollerate alchol or standing for too long, I sleep a lot of my life away, I am living a nightmare, the NHS just wont recognise how poorly I am, this is really starting to affect me as I keep relapsing but have nowhere left to go as my GP and LD dr have told me I DO NOT have Lyme disease even though I had a bullseye rash after being bitten in Portugal 6 years ago, and have been so ill ever since, and I have a posititve Armin result,not being believed is turning out to be the biggest nightmare, my husband has written to our local MP as he feels desperate to get me some help, he sees me when I am at my worst, and it scares him, during my last relapse I couldnt walk, I couldnt put words together, I had no memory of anything, I couldnt remember how to do simple tasks, I was in agony with headaches, sharp pains in the right side of my brain, numbness, joint pain, and the NHS say its not Lyme but they dont know what it is! and tell me to just get on with life, they will not acknowledge how ill I get and how frightening it is, what do I do? this disease has stolen my life from the age of 45, my husband is an armed officer in the CNC, ex policeman, we should be enjoying our lives, and doing the things we want to do in these last good years, but my health is stopping us, we are at a loss, I feel angry and guilty that our lives are so compromised, you only get one life, and I am being denied treatment that could dramatically improve my quality of life.

i cannot work, I no longer go out or socialise, myself my fiancé and 3 children all have Lyme so it's been devastating to find out we caught it from tick bites whilst on holiday.

Before Lyme disease I was very active with running, gym, exercise classes, dance yoga. My quality of life is now almost non-existent. I am suffering poverty from trying to pay for my own treatment. I can not work. I have tried to do part time courses and been beaten back by fatigue and exhaustion making it impossible to continue. I can only cope with the absolute essentials of life and sometimes can't even do those, shopping cooking, a little house work, showering. My days are short because i need to spend so much time sleeping or resting. Some days I can't make it to the shops when I need to so can not eat healthily if I don't have the food in the house. I had to give up my internet and land line so cannot do online shopping any more. Lyme disease has seriously strained my family relationships and friendships. In spite of this my adult children are the only thing keeping me going. I make plans to see friends and have to cancel because i can't even get ready to go out. Many times the sun is out outside and I want to go for a walk but can't even get dressed. I cannot go on holiday both because I can't afford to and because I wouldn't even be able to make it as far as the airport. I have only seen my ageing mother, who lives nearly 200 miles away, once this last year because I have been too unwell and can't afford to. I need to sell my home as i can't afford repairs or replacing worn out and old items but dont know how i would be able to cope with moving. Brain fog is so bad i quite often I don't want to talk to anyone on the phone in person or by messaging as I feel like i can't get my brain to function properly to organise thoughts, words, listen or even have the strength to hold a conversation.

Quality of life changed drastically for three years.

Luckily I was a retired teacher when I developed Lyme Disease, there is no way I could have worked with such debilitating symptoms. I went from a highly active healthy

person who enjoyed exercise to someone who felt very ill and had difficulty getting out of bed daily.

Had to push myself on a daily basis to get through each day.

With no consultants available in UK my life became totally focused on Lyme Disease information available online

and my survival instinct kicked in as I battled alone to find the best way forward.

I believe Lyme disease has affected my life immensely my symptoms started at puberty, and I've struggled with depression, anxiety and fatigue for many years. I believe there is a possibility that Lyme could run in my family with my mother having undiagnosed symptoms and possibly even my late grandmother. I have a cousin who has fibromyalgia, and there are mental disturbances within the family more than I believe to be normal.

I suffered a coma age 14 after a tick bite in 1986. They didn't link it or know it was Lyme. On return from the hospital i heard and saw things. Was unable to walk properly or concentrate. I could not think coherently at school. I became depressed and suicidal. I self injured. I had extreme migraines and horrific muscle weakness. This progressed throughout my life into my 20s and 30s until I was wheelchair bound with my oldest daughter as my young carer. I was finally diagnosed age 38. By which time I had been told I had depression , fibromyalgia , ME ETC. my oldest teen is the only congenitally admitted Lyme case we know of as she tests positive on NHS also. She had bullseye rashes within days of being born.

Yes! I went from being a super Mom, Gym Rat to now a Super Sick Lab Rat. I still count my blessings everyday, and stay hopeful dealing with this awful disease. It's changed my whole Life! It's been a roller coaster ride!

A complete life changer. I have sold my yoga studio business as this month I have been unable to walk, speak well or swallow easily. I am used to teaching 10 classes a week, Saturday workshops and teaching yoga retreats abroad. I cannot drive at the moment as eyesight is blurred. I am having to rethink how I will make a living. My husband is a pensioner so would not be able to support both of us. There are times when I need full time care. I was, and hope to be again, a fit person with an active outdoor life. On good days I can walk for 30 minutes outside and on bad days I cannot move my legs. My social life consists of hour visits and half drunk cups of herbal tea. I hope that I can find the way out of this tunnel and do some good for others. I feel so ashamed as have had to apply for PIP and am terrified of having an assessment to see if I can have some financial help.

Had to cancel two holidays last year so husband missed holiday as well.

Too tired to socialise because of exhaustion and anxiety.

Unable to walk for very long before body pain increases.

Afraid to leave the house because of pain and anxiety.

Disappointed with GP practice about their attitude and lack of support towards Lyme disease, hence having to pay for private tests, if only for my own peace of mind. Then having my positive tests dismissed by GP.

Wrecked my life. Too ill to work because of Lyme disease since 2009. I had to stop my successful home tutor business (which I had set up after leaving teaching when my baby, first child was ill in 2006) dire financial situation only one wage now. Social life none existent too ill. Too upset to write more...

Sudden onset of extreme fatigue in May 2015, random pains, headaches, Palpitations and chest pain, memory loss, lack of concentration. Weight gain and bloated tummy. Have hardly been able to attend school during a very important last year of 6th form, had to give up part time job. Socially cut off from friends. May have to repeat last year

of school. Still await recognition of Lyme diagnosis in Uk and coinfections. Still await treatment and accurate advice on how to cope with and cure this complex disease.

My quality of life has suffered in every way possible.

I was bitten & infected with this stealth pathogen 22yrs ago, no doctor knew what was wrong with me. I was affected suddenly & severely forcing me to go from full time employment, recently having being promoted, to being bedridden. As a family who lived a very happy outdoorsy life, we were plunged into financial ruin practically overnight as my family became my carers affecting my young childrens school life & my husbands work life. I was a devoted wife & mother to my two young children. I thought i was dying, my family thought i was dying. The doctors had no idea what was wrong with me. Having to explain to your children that you might not always be around for them but how you will watch over them always, with quiet tears streaming down your face, my face, is something i do not wish on anyone, but that is how badly i was affected, it was a horrendous situation impacted by the ignorance of the nhs regarding lyme disease. There was no education, they knew nothing then, they know nothing now. Due to patient led awareness nhs now know of lyme disease but they do not know about lyme disease, far from it.

I have suffered so severly with this disease & at the hands of the nhs by their total abandonment. I have no social life to speak of, my family are my life, if it wasnt for them believing in me, witnessing everthing i have been through, caring for me, i dread to think what would have happened.

I was a sociable outgoing person. Happy wife, and mother to two amazing children. I worked full time I LOVED my job. I was also a member of a musical theatre group and performed in two, week long run shows, inc matinees, per year. My husband had found a new and promising job we truly thought things were on the up for us.

Now I cannot leave the house sometimes I cannot leave my bed. I spent over a year entirely bed bound and unable to even go to the toilet without assistance from my

husband. I cannot speak for long and due to transient paralysis with sensory overload sometimes I can not even hug my children. This disease has robbed my children of the mother they knew, and my husband of the wife he married.

I lost a job that I adored, and my husband had to give up work also to become my full time carer, and full time Dad for the kids. The impact on us financially has been huge, but lucky for us, our cupboards were kept stocked with food, and the kids never went without, thanks to our amazing family and also a generous food hamper at Christmas time from the community church, and my Lyme treatment is paid for by family and friends fundraising. I know that not everyone has the support system that we do and for that, I will be eternally grateful.

It has ruined it, isolated

I was about to Grad Uni as a Psychologist and with an offer to work in USA with Masters to do on rtn. I collapsed at Uni and have not been able to do much since. I am bedridden some days, exhausted after a few hours on good days. I have no social life and was left on £75.00 a wk by DWP who denied me PIP initially. I faced a tribunal and was made homeless by my parents who did not believe me. I was left with no care and no home. The NHS misdiagnosed me with ME despite my telling them I had been to Lundy Island, Richmond park on frequent studies and grew up traveling and hiking outdoors. I was bitten but recalled no EM and was not sure by what. I was told it was PVFS then CFS then ME and anxiety disorder despite my natural relaxed nature. I am now 37 with no house of my own, no kids and no family support and no treatment. Instead the DWP send letters to check bank statements. The Gov have spent more ridiculing the sick then treating them

Lyme has damaged my brain (bbb) so much over time that my brain became vulnerable to other chemical toxins, which nrought me down and nearly killed me (still recovering) gp and nhs services wont accept toxic event and allergies so cannot help

me safely as cannot understand my symptoms are part of neurological acquired condition (nhs not equipped for toxic brain injuries) which so called nhs neuro tries to label MS (none of the typical symptoms at all!!)

So the highest damage is loss of trust in nhs for anything else than blood injuries, heart surgery and (maybe) cancer.

I was a high tax rate payer, just asking for help so i can get on with life again and pay tax. What waste of money. What waste of my economic potential (entrepreneur)

My conclusion: nhs are paper pushers apart from A&E who do amazing job. Sack the rest.

I was thirteen years old when my symptoms first appeared. I can only manage to attend school part time when I am not too ill, I have started my GCSE's and cannot manage much other than resting and keeping up with my studies because I don't want this disease to take away the choices I have in life. One day I would like to be able to go to medical school and help others with autoimmune diseases.

My mother has had to give up work to care for me and help me keep up with my school work. I spend a lot of time on my own, apart from one great friend most people don't understand chronic illness and a lot of the girls at school think I am faking my illness even one of my teachers does too. Really I fake being well because I always feel ill.

I was at a selective grammar school and was expecting to do well academically and go to a top University. However, I became too ill to attend school, had to leave before GCSEs and I am now floundering academically due to fatigue and brain fog, There is little hope of getting to University or having enough energy to hold down a job. My single parent mother took redundancy to support me and wont look for another job until my future is more clear. We have given up on the NHS and am going to the USA to see a Lyme specialist. My father died, leaving me some money that I am using to pay for this, so I am one of the "lucky" ones.

Lyme disease has stolen my life away from me.

My life has changed beyond recognition. I enjoyed active outdoor activities & had a varied social life with both work, freinds & family. Because LD. Has so many symptoms it is now impossible to enjoy ANY of the above.I am in constant pain & have frequent bouts of CFS. Naturally I can't work (scientist) & financially literally live hand to mouth, depending on my son to wash, help dress me & generally look after me. Frequently I can't move..It is soul destroying for anyone like myself who WAS very active &had so much to give to society.

The disease has changed my life completely from being a normal healthy woman to a fraction of the individual I once was. I live day to day mostly hour to hour managing an illness that is so complex. Financially Lyme disease has destroyed my ability to work full time and I now only work in the season (summer months) part time as the winter months are too challenging and I am pretty much housebound. For 2 years I was on a range of painkillers that I became addicted to. I believe this happened due to ignorance from my doctor and Lyme specialist. I am now free of all painkillers with the help of a Homeopathic specialist. I had been taking 2 pain blockers, gabapentin, co codomal and ipubrofen. In December 2014 I went cold turkey, not an easy road but I succeeded. I now manage joint pain with resistance bands and light weights. I feel very let down by the NHS. I was misdiagnosed by 3 doctors! One of them I saw 3 times and he made me feel I was crazy in the head! The sad thing was I was going crazy as this horrible tick bacteria was through my bloodstream and affecting my brain by attacking the nervous system. Family life well I am fortunate to have a loving partner and caring son who could see their mother extremely unwell with no help out there but a doze of Doxycycline 3 months too late and a pile of painkillers to numb all the feelings of confusion, anger and despair. Having Lyme disease is similar to grief. You are upset, angry, explode and accept that for now their is no cure but always have hope! I am so

used to feeling unwell it is a new normal. My life will never be the same but I will live in hope of a cure.

Tiredness not all the time but when hits can sleep full 48 hrs..joint pain in knees had to give up certain sports. When take ill ie bug will b off feet for at least 5 days hits harder and longer.

I cannot begin to explain how debilitating this disease is. Having had kidney cancer I can honestly say given the choice cancer is easier to live with. I know Lyme doesn't kill you, but the constant battle to get well only to be dragged backwards is seriously depressing. I often feel I cannot cope with it any longer, but of course you have no choice and continue to struggle through the days waiting for it to lessen in intensity.

It's ruined everything. Even my ability to think & write

At one point I thought I only had a year or so before I would be dead, I was losing my sight, unable to walk, I had many cognitive problems, in truth, I was very ill, and I wanted to die.

I had come to terms with the illness and felt that I did not want to live for much longer based on the way my health was deteriorating and I felt like I was burden on my wife who has Multiple Sclerosis and her own problems to deal with.

The NHS and the inadequate response to my illness has forced me to go down the route of self treatment via herbal remedies since I could not afford private treatment that my GP suggested.

I am now in a much better place, I am feeling relatively due to my own research and a little bit of luck finding things that worked for me purely by accident.

I grew up thinking that when I became ill that the NHS was there to help me in my time of need, I found this not to be the case. One of the GP's that I saw when I first became ill was at best unprofessional, and at worst dangerous.

I live in a Lyme endemic part of Scotland, was bitten by a tick, had the EM rash at the bite point, but I was told that I could not possibly have Lyme Disease or a Coinfection since my ELISA test was negative. My Infectious Disease Consultant has 'complete' faith in the ELISA test and therefore did not believe I had Lyme, but told me (verbally) I had a 'chronic infectious disease', yet he wrote to my GP saying that I had chronic fatigue syndrome, and later denied he had ever told me I had a chronic infectious disease. I have had to fight to get any treatment from the NHS, and they still appear to deny that the tick bite was the cause for my illness. I am not the type to claim to be ill if I'm not, I haven't had a cold in over twenty years. The ELISA test is inaccurate, both GP and consultants knowledge is inadequate, the UK is way behind every other country on Lyme treatment and understanding that this is a long term illness that requires long term treatment, rather than thinking that all tick borne illnesses can be cured with one 3 week course of Doxycycline.

Major impact in all areas but am not willing to be specific

I became unwell when studying at the university of Exeter. I completed my final year of study mainly from my bed instead of going to lectures or socialising like a normal student. Since graduating I have not worked, I socialise very little and struggle to be out of the house by myself so much so that I am mainly housebound. My mother cares for me and I have spent a portion of time in the US receiving medical treatment. On bad days I can barely lift my head off the pillow. This is not the life a 23 year old graduate should be living. I previously played sport multiple times a week, spent hours and hours studying whilst still having a busy social life. This is now all gone thanks to Lyme disease. Without the help of my amazing US lmd I feel as if I might not be here, because of him I suffer less and less each day. Wake up nhs and help us! It's ridiculously unacceptable the way we have been left to rot. I consider myself fortunate to have a family wealthy enough to pay for my treatment. I am also thankful that I myself have been able to research and get to understand this complicated and devastating disease.

The fact that I know more than most uk doctors I go to see about Lyme is just unacceptable.

Massively. I don't think I'll ever be fully recovered. Although I can now work again, my number of sick days has increased, it's hard to keep an active lifestyle and the fatigue and underlying health issues have caused mental health problems.

I am now unable to work in my previous job and have a very restricted lifestyle, having to stay in and rest much of the time and unable to even participate in most social situations due to fatigue, vertigo and 'brain fog'

I have NO quality of life. Just a miserable painful existence. I cant work. I don't socialise anymore. I'm reduced to living on benefits(the amount I receive per MONTH is not much more than what my WEEKLY (take home) pay was. (Yet the DWP treat you as though this is a lifestyle choice) for over 10years I was dismissed by NHS as being 'anxious' as they couldn't find anything wrong with me, the worst thing is, since I did their damn job for them (via google)and requested testing for Lyme and co, (and consequently positive results) the treatment meted out has been ever more appalling.

I had a career that I loved with HMRC for 24 years but lost my job through ill health. I no longer get any ESA as my husband works. I have developed sensitivities to food and chemical sensitivities and in the last 12 months have unexplained weight loss of over 2 stone. I am so sensitive to perfumes, car fumes etc that I no longer have a normal life. I cannot go food shopping, get eyes tested, dentist, haircut etc. I cannot even visit my GP as they use air fresheners. I cannot go in my garden if the neighbour has window open due to their air fresheners, or has washing on the line. My only trip outside is a walk with my husband and dog in a field when nobody is around. Sometimes I still have to wear a face mask. I do not see any members of my family at all as I cannot deal with the laundry products on their clothes. I can use no perfumed cleaning or personal

products. My dad died of cancer last year and I had to say my goodbye to him over the telephone which my mum held to his ear. The flat he lived in had a real problem with mould and I could not visit because of this. I could not go to the funeral. Without the support of my husband I would not survive. As I write this tears are flowing for the life I once had. I used to be so confident and assertive and now I hide if somebody rings the doorbell.

Yes im in a nursing home lost a baby n am a paraplegic who has been in 18 major comas still suffer little comas weekly have seizures daily loss of soeech n swallowing

Lyme / MS has affected me very dramatically over the last 8 years in particular (there is evidence it goes way back beyond this though). I ran a succesful small business and was (in financial terms) pretty much a millionaire on paper. That has all gone, as has my marriage and to some extent social and family life. It will not however take my spirit!

I'm not blaming the NHS, but had the time been taken to properly diagnose, things may well have been a lot different.

I am now on antibiotic treatment for Lyme and things are slowly improving

I have a dream of creating a "Safe House" for people affected with lyme disease complex, to provide a safe heaven for those days/weeks when someone is so ill with this that death feels imminent and the "medical professionals" who should just don't get it and don't care to try.

I am a mother who is never totally well and I have not been able to do many things with the children that I wanted to, my long term relationship broke down, I have poor health, but it has been worse (prior to the long term antibiotic treatment that likely saved my life!), thus I am financially very poor too (I have paid for my progress in health) & should I say I am in a 'medically induced' debt, still unable to work,

dependent, cannot even drive, upset/angered/annoyed about the arrogance and level of ignorance of too many medical professionals.

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I am now on antibiotic treatment for Lyme and things are slowly improving

I am 27 and while I am able to work, I struggle through every day and my weekends are spent in bed recovering from the week. People think I look fine but I'm not, my whole body aches, my throats sore and I feel like the world is spinning. Sometimes i'm not sure how I'm able to walk.

I have no social life, constantly letting friends down as I wake up with a migraine or i'm too weak. If I do manage to do anything I have to keep the next day free as I know it'll be spent in bed and when I wake up that day I regret the day before instantly. I am unable to do simple tasks like cleaning without it draining my energy.

I've just got engaged and should be planning the wedding, enjoying my time with my fiance. Instead I spend my time sleeping and in pain.

Lyme disease has prevented me from working and earning a salary, being an active mother, being a loving wife, being a good friend. It sucked all the life out of me.

I lost my business and friends. Unable to manage my financial affairs or work. I socialise about once per month nowadays as any more is exhausting.

Previously a higher rate tax payer, talented artist and pilot and contributor to society and local businesses providing guidance to businesses as Vice Chair of the Federation of Small business Surrey region and a British Female Inventor winner of many awards, all now seems a distant memory. I am very angry at the Government from stealing this life from me and the utter abject stupidity of those who run the NHS. The Lyme debate is a disgrace and those who have ruined lives have blood on their hands and my money in their hands. Where is my NHS treatment which I am entitled to?? I have had to pay over £50k just to be half alive! The ignorance in the NHS is abhorrent and manufactured by those who want to promote ignorance and suffering as it benefits their aims in hiding the truth. Truth is like the sun, you can shut it out for a while but it will always be there!

completely i have no quality of life i cannot work i used to drive ride my horse its all gone now !

I'm 37 yrs mother of two and depend on my parents where they should be depending on me I can't do things in life people take for granted socialising ,just getting ready or general looking after your family

I work as a community nurse for the NHS. The first time I approached my GP with multiple symptoms I was told that if I had more than one symptom I needed to make an appointment for each one. I had so many symptoms it would be impossible. My daughter has Lyme disease which was diagnosed in UK but she was unable to get treatment and so went to BCA. She knew my symptoms and she suggested I get tested in Germany so I sent my bloods off to infectolab and they came back positive for Lyme and other co infections. I went back to the GP with my blood results and told her that I was going for treatment to Germany. She said she knew nothing about Lyme disease and to come back to see her in a few weeks when she had time to research it. When I went back she said I was wasting her time and the money of the NHS. She was

rude to me and told me to be quiet and leave. I was shocked by her reaction and I changed to another GP surgery. She had referred me to a consultant for rheumatology because of the pain in my hands (the only symptom she was interested in) and although I was now with another surgery I went to the appointment. I didn't speak to him about Lyme disease. He never asked me any questions about Lyme or mentioned it. He took no blood tests. Then I got a copy of the letter he sent to my previous GP to say 'This lady definitely does not have Lyme'. Through these experiences I have a distrust of doctors and their opinions.

I am in severe pain every day in my hands, shoulders and right hip. I have pins and needles down one arm, I have nights when I do not sleep at all and then have to go to work the next day. I didn't know my inability to sleep was a symptom until I started antibiotics. From the first week I was able to sleep but since stopping them I am back to not sleeping. I am not so ill as others I have met and heard about.

I have struggled to stay at work for the last 6 years. I have one year to go to retirement and I don't know if I'll make it. I suffer from exhaustion. When I return from work I shower, eat and go to bed and hope I can sleep so I have the energy to go to work the next day. At work I could have taken a promotion but because of constant symptoms, especially exhaustion, I did not feel able to take the extra work and responsibility on. The result of that is that my pension will not be as good as it could have been.

I have an elderly mother and other family living 200 miles away and I do not have the energy to make the journey to see them. I miss out on all the family social events because I do not have the energy to go. I have no energy to see friends. My social life is by phone or Skype.

I have been receiving treatment in Germany for the last two years and there has been an improvement in some of my symptoms. I have had a persistent cough for the last 7 years. NHS doctors x 4 diagnosed acid reflux from stomach I told them it was not acid reflux but they weren't interested and gave me proton pump inhibitors. The German clinic is treating me for chlamydia pneumoniae which showed up in infectolab blood tests and I am now on herbal meds for that.

I am not a rich person. However I had savings for my retirement. So far it has cost me about £13,000 to travel to Germany for treatment. The blood tests are expensive but the treatment and appointments at the clinic are not so expensive in comparison to private treatment in UK. Most of the money went on travel and accommodation costs in Germany.

Even though I am a nurse working for the NHS after I read about others experiences and also hearing my daughter's experience of trying to get a diagnosis in this country, I didn't try to get a diagnosis and treatment through the NHS. I had the money so I went straight to BCA in Germany. I didn't have the energy or the time or the emotional stamina to bother with the NHS.

Total Devastation. My son had to give up his job at the BBC and has not worked full time for over 6 years.

From a career driven hard working person, I became desperately ill. I was given Amitriptyline which masked my symptoms and did not actually address them. For almost 14 years I have struggled. 4 months ago I went dramatically downhill. I have been self employed for 4 years, if it weren't for my mum, I would have lost my business.

I travel to see Dr Jemsek in Washington in March. There are about 10 UK Patient all flying within the same month, to the Clinic. I have no idea if I will make the flight, I am so incredibly ill.

My GP has prescribed nearly 4 months of an antibiotic combination of MY choice to get me well enough.

I have no money, hardly any savings and no property. All in all, 14 years of hell on earth.

I, and my family lost over 2 years of my life. Bedridden and wheelchair ridden, my family watched me go from a dynamic young woman to a mess. I had to give up work,

and had no quality of life. On top of that the NHS offered me no treatment, even after I presented them with several private blood tests showing them I was infected with Lyme disease. Instead they seemed to be persistent on diagnosing me with a 'functional' or psychological illness, as they could not provide me with an organic diagnosis. They were just not listening to me. Left on my own to pick up the pieces, I continued to seek answers and was determined not to give up on life. With the help of friends and strangers we raised a vast amount of money (over £15000) to go to Germany and begin treatment with antibiotics. It was gruelling and painful but within weeks I could walk unaided and after several months I really began to see my health improve. 2 years on I am like a different person. I still suffer with, mainly the repercussions of a longstanding undiagnosed illness, but I am a whole load better. I still cannot work fulltime but I can walk, run, eat, laugh, live, have conversations and above all I have energy. I am living again, something I thought would never ever happen again.

In every way possible...please Google my name for I've been in all national newspapers t.v radio

My quality of life has been horrendous. I haven't had a social life for two years and I am amazed I am still working but I don't know how much longer I can take it. I had a private test done from armin labs which I had to use a credit card because I have no savings. I am writing this now sat in bed on a saturday afternoon drained and in pain. I was off work for a month over Xmas my whole body just shut down I could not eat properly and the anxiety was that bad I couldn't leave the house. I live on my own in private rented accommodation, I push myself to go to work everyday just to keep a roof over my head. working everyday with this disease just makes me worse I have constant migraines, body tremors, dizziness, fatigue and allergic to everything and is near impossible to do my job properly due to the symptoms. I just want the proper treatment so I can get on with the rest of my life I am 38 next month and I have had this since my early 20s it's only the last two years it's been making me really ill

attacking my stomach and joints and I am starting to get neurological symptoms. The mental and physical abuse of this disease I do not wish on anyone.

My life and entire existence has changed drastically since I became ill with Lyme disease 4 years ago. I went from being a very fit, healthy and active independent woman to practically an invalid who is 95% housebound and reliant on family to help care for me. I lost my job as I'm too ill to work and as such couldn't support myself, I now am on benefits (ESA). This I am grateful for yet it's demoralising as I am a proud person and always been independent and able to take care of myself. I live with daily chronic pain and debilitating fatigue. I have lost faith in the NHS completely when it comes to assisting me or others with Lyme disease. There are many many people such as I who are seriously ill and yet we are being tragically let down. I am a pretty tough cookie yet this illness has left me in a terrible state and unable to cope in just about all ways, I have often thought of suicide when things become unbearable. Surely this is no way to treat those of us who are afflicted with such a debilitating illness such as Lyme.

My life has changed dramatically; I lost my job which was a good career 4 years ago. I'm now 98% housebound and rarely go out. I literally hobble around in severe pain. I have become very isolated and depressed and rely on my son to do basic tasks for me as I cannot cope with most daily necessary activities like cooking, cleaning, taking the bins out. I have spent a large proportion of my life savings on tests, private consultations and supplements and this has amounted to thousands. I worry that I cannot continue to afford to spend money at the rate I'm spending because I'm now on benefits after earning a reasonable wage. The isolation is terrible; I'm not well enough to go out and not well enough to have people visit. My family do not really understand the extent of my health issues so I feel abandoned. Friends do not get it and we drifted away from each other. My partner left me because he was tired of my illness. My son gets anxious because he worries about me. Every minute of every day is full of severe pain and limitation and I have had to research and find protocols and supplements that

could help my diseases. My lyme has stopped me from utilising thyroid hormones so I'm very ill with thyroid too. I'm a shadow of the person I was. My doctors are not at all understanding and just keep offering more anti depressants because they believe that lyme is 'cured' with a few weeks of anti depressants. I often want to die because my existence is so horrible but my will to live is strong because of my son. It is a terrible place to be because the disease is not understood or treated correctly leaving the patient to be misdiagnosed or seen as a psychiatric case. The support from the NHS is totally inadequate. I'm crippled and emaciated and am labelled as a stressed out person by the NHS; someone who has pain because of depression but the reality is I can barely walk for joint, bone and muscle pain that radiates throughout my entire body severely and even up my spine and into my head. I barely sleep for the symptoms and go through each day like a zombie full of pain and anxiety. I honestly feel like I am dying a slow death in a painful manner and yet disbelieved by NHS. I have been told by some GP's that I might have ME and I'll just come out of it one day and look back and think "what a horrid time that was". How I wish this were true. It is a very isolating, misunderstood, expensive and agonising disease.

This really hurts to reflect and answer this as I am someone who tries to not look back and just keep going, one day at a time, to get me through this Lyme ordeal.

The consequences of this disease as I consider these question is HUGE and makes me cry thinking about it. But if it helps people to understand then I will answer in an open way ...

How has Lyme impacted my career?... After my mother suddenly died I decided life is too short and decided to pursue my lifelong dream of studying Art. As a mature student in 2008 went on a part time Art/Design Foundation course.

This was a challenge as I had a ME/Fibromyalgia diagnosis I was also a single parent of a young teenager who had her own "special needs" born with a heart defect etc. But I was determined to manage a part time course and pace myself and my daughter had made great progress life was on the up!

Despite my struggles with the course work and health my tutor put me forward at the end of my first year for a "Student of the year award"

I attended an award ceremony and won a prize and along with a trophy with my name embossed as Student of the year 2008.

I felt immensely proud and hopeful of my future prospects.

I got distinctions for my work and my future looked bright was offered 3 unconditional places at all the universities I applied for. I went to Brighton University to study Fine Art Sculpture.

I was doing extremely well getting top marks until my daughters health declined and this in turn had an acute sudden impact on my own health.

I was no longer able to continue with my studies or give the care and support my daughter needed.

Due to "new debilitating symptoms" I left University in my second year and have been unable to go back to complete my degree due to tutors stating that I was not fit enough to manage the criteria of the final year and get the grades that reflected my true abilities.

My peers however, have gone on to great success and exhibited work nationally as well as internationally.

I was expected to do likewise but lacked the ability to put words together or find the stamina and strength to fulfill the criteria.

I was even offered work to assist a well known artist but had to decline as I was unsafe to drive a car and unable to work full time which the job required.

I had in 2008 begun a relationship which ended two years ago we were engaged to be married but without going into too much detail it is safe to say that being in a relationship with someone who has an illness not recognised by the NHS who is not getting treatment therefore not getting better who is not getting out of bed who is not contributing to the bills who is often in bed when you return home from a hard days work looking exhausted and not always pleased to see you simply because the inflammation in their brain is causing the mere sound of words like "Hello Darling How

are you and what have you been up to today" feel like bullets shooting through your brain and besides its hard to decipher the words,the order etc
so then you reply with a torrent of expletives to stop the barrage of words from insulting your sore brain...you just want it all to shut up and go away...my partner tried positive affirmations tried picking me up of the floor, giving me prompts and reminders to start and finish tasks, kept thinking it was mind over matter kept believing that he could "fix" me I became so broken and misunderstood that in desperation I ended the relationship because I could not stand trying to think myself into anyone else^s ideal of how I SHOULD BE!

In past two and a half years I have faced a further ongoing decline of no family support, no relationship or chance of, no financial support except living off benefits,loss of friendships,lack of emotional support, no hopes or dreams to look forward to just a society that keeps telling me I need to exercise, take up hobbies,make art!! sing, go to CBT, think in a positive way,get some sunshine,rest up,too much rest,don^t eat sugar,eat more vegetables, the list goes on....this has taken me 4 hours to write I am struggling with punctuation and mistakes I want to put right but have to leave it my brain is shutting down hope this helps someone understans

1. I have recently learnt that my daughter may have a heart defect as a result of the possibility that I passed the infection on to her while in the womb at some point I hope to have the money to get her tested but this is another area that is not recognised in the meantime she could have a baby and spread it to both her partner and unborn child.

I used to be a productive IT engineer with a great career. I should be earning £100,000 a year by now, but instead I'm surviving on benefits that are barely adequate because I'm so ill I can't cook for myself properly so if I want something nutritious, I have to have a chicken salad or something delivered. I can't afford that!

It has affected me specially the Fibromyelgia. I am not given the appropriate pain killers. Which are many but they keep saying buy Panadol from Chemist.

I wish NHS will scrap the PC's from surgery's. There is no more eye contact while they are gazing on the screen.

I have been a carer for the past 7 years every other week. Since problem with my neck i have not been able to do this, I AM DEPRESSED.

I am 78 on my own.

Pain . No energy. Num

Dizzy. Can not think.

I've lost my life. I'm just not dead.

I worked full time as a community midwife, with a great social life, lots of friends and interests. I was so sick, I was unable to work, Occupational health dept wouldn't let me return and eventually after a year they terminated my contract, as I wasn't able to work, I wasn't able maintain my registration as an RGN/RM so I pretty much lost my identity, income, colleagues and most of my friends. I became very isolated, depressed, managed to hold on to my marriage but only just.

I am in a much better place mentally, have accepted my lot. simple things such as brushing teeth is often a struggle, self neglect easily creeps up on me if not careful.

Family get care fatigue (frustrated as they really don't get it although they try) I avoid any mention of ailments within the family as I got tired of the eye rolls.

I was always a keen crafter, knitting, corchet etc, I couldn't apply myself for long enough to even start a project until very recently and it helps lots, but I can't imagine ever enjoying the quality of life that I used to have. Lyme and morgellons have robbed me of my credibility, validity, and place in polite socitey.

I missed 4 months of work and suffered considerable pain, as well as the anguish of not knowing what was wrong with me, whilst very slowly being passed around various NHS departments. I'm left with a degree of discomfort in my hands, wrists and elbows which is manageable but constant.

yes i struggle to get through the day some days. i constantly fear losing my job from underperforming

My life has drastically changed since Lyme disease. I can no longer work, I am mainly bed bound so it's completely changed my life.

from been very healthy too been house bound unable to work on the families farm no wage coming in unable to be a full time mum anymore unable to drive have to sell my horses cant ride anymore

RUINED RELATIONSHIP COULD NOT WORK CANNOT ENJOY MY CHILDREN AND GRANDCHILDREN NO SOCIAL LIFE AT ALL

Before I got Lyme disease I had my own bussiness, I had a very nice house with 2 ackers of land, I had good health, I could drive, i had a long term partner of 20 years, I had savings. Now I have No bussiness, No house, Very bad health, I can not drive, I have no partner, I have no savings, I have spent about £10,000.00 on my health, now i have no money.

I was a graduate manager working in an engineering environment. I became unable to think, speak, write, drive safely in 2003 so I had to stop working in a high risk environment. I moved to a consultancy role. That became too much and in 2004 I had to stop work as I could not stand upright at this point, I was slurring my words unable to communicate and I struggled to see and toilet myself.

I was diagnosed with Lyme in 2005 and with one year of nonNHS antibiotics I returned to nonprofessional work one day per week. After continuing on antibiotic treatment a year after that I started some part time distance learning which has allowed me to retrain professionally. I hope to complete my practitioner doctorate this year. I am now working 4 days per week professionally. It has taken more than a decade of treatment to recover to this level. Only this year have I been able to engage in aerobic exercise and restart cycling and hill walking again, which are my passions.

In term of lost income my husband and I have probably lost in excess of £800k between us plus lost pension contributions. Probably more. I was on sickness benefits for 11 years.

We have been unable to have children because of the severity of the symptoms and now the treatments. I'm 42 and it does not seem likely we will start a family. My health while now pretty good is fragile and I have evidence that I remain infected with the borrelia bacteria (not from an approved laboratory though).

Robbed me of 20 years of my life. At 40 years I felt like 60. At 65years I feel like 85 year old. I was an extremely active, fit and healthy woman looking after home and family and working part time in my career as a teacher.

After I became ill, without any diagnosis other than "a summer virus" I was left to find a path to recovery on my own. The surgery had known me fit and well so examined and tested for all possible causes of my "New symptoms" : arthritic, IBS, fatigue etc and found nothing.

I used to joke that I was the most organically sound person I knew and at the same time the illest.

I had to hide the full extent of this debilitating illness from my employers, my colleagues and acquaintances as well as my children. My life, my world, shrank to almost nothing. Only my very close friends continued to support me.

This illness compromised my career opportunities, my Post graduate opportunities, my social, personal and family relationships. It even put me through the HELL of self

doubt and a painful journey of self examination to find a PSYCHOLOGICAL explanation for my symptoms. In vain.

NOW my HUSBAND is infected!

Did I infect him?

I was a relatively fit person before the Tick Bite in 2009. When I visited the GP with this circular 'Bulls eye' rash I was told I had Lymes I went away with 7 days of blue capsules and thought that would be the end of it. Not so! I used to be a jolly lady. I loved the sun, adventurous with food and wine, slept like a log, only had the usual pain in my back for a tall lady. My health very quickly deteriorated with a myriad of symptoms so I saw 8 different consultants to try to get a diagnosis but the N.H.E. Blood tests proved negative so, although I have All the classic symptoms no one will prescribe long term antibiotics.

My life has been hugely effected. I no longer work full time which has a financial impact. I'm unable to do so many of the things that I used to do because I'm in pain and exhausted most of the time. I used to be career orientated but now I simply go to work because I have to and spend all my time outside of work recovering. I used to be happy go lucky but I am now on antidepressants and struggle daily with the changing symptoms. My family have been a huge support but my relationship broke down partly because of the pressure of my constant illness and financial pressures that this put us under. In short my life has changed completely and without proper recognition and understanding I am left not knowing if it will ever get back to some semblance of normality.

Makes life hard as I am a mother of two small children. I can't take care of them properly and need help. It puts a lot of pressure on my husband. I miss out on a lot.

Ended marriage, ended job as f/lance writer for BBC. Chronic fatigue rendered me, virtually a recluse.

Slightly over a year ago I went to my GP after developing a rash (not a typical bullseye rash, but a large red blotch which spread across my abdomen. I wasn't so worried about the rash, but more concerned by the others symptoms I experienced shooting pains/twitches, lack of sleep/poor quality sleep, fatigue (sometimes extreme and often spontaneous), sweating, stomach pains, headaches/pulsing head, stiff neck, etc. The symptoms came and went, as did the rash. I visited 5 different GPs in my local surgery. I was treated for a fungal infection, however the rash did not respond to the treatment, but would flair up and fade away of its own accord. I was initially asked to take ibuprofen as this helped with the swelling associated with the rash. All of these symptoms persisted on and off, waxing and waning in severity, from November 2014 through to June 2015. During this time I started a new job, and frequently found it difficult to focus at work, feeling 'misty' or 'fuzzy'. At times i often felt very anxious, worrying about what was happening with my health and just as my symptoms seemed to be fading, they would reccur, or a different symptom would appear. I'm generally happy, but this was/is extremely frustrating. I'm in my 30's, have worked since I was 18 and only ever been off work due to illness once in my life. I haven't let this stop me going to work, but when symptoms flare up at work this can be distracting. I've found myself having difficulty focussing, which can be problematic when trying to talk to colleagues or doing presentations. Before this illness, I rarely went to the doctors, but have attended frequently since. I have gone from someone who was very rarely unwell to someone who frequently experiences the above.mentioned symptoms. I wasn't a big alcohol drinker beforehand, but now if I drink a bottle of beer I almost instantly feel tired and often feel horrible the next few days. I almost never drink now. At my worst I felt horribly tired and would break into a heavy sweat, wanted to badly to rest, and wasn't able to exert myself. I was running marathons, cycling, hill walking, etc prior to my condition, but feel likes it been harder to exercise. I feel like exercise helps me

when i can do it, but at times i have been simply too tired. One of my GPs referred me to have a heart trace as my heart rate was low (though I've always had a low resting heart rate) but the test results were normal. In the summer i had a couple of months when i was virtually symptom free, but in September 2015 they returned and i found it very hard to concentrate and was very tired, had a stiff neck, headaches, stomach pains, shooting pains many of the same symptoms I'd previously had. I went to a new GP surgery and the Gap ran a battery of tests which all came back negative apart from the Lyme disease yes (I'm not sure which one the GP used) which was positive. Its the only thing I've been diagnosed with since having this bizarre array of symptoms. Unfortunately, i wasn't told anything about the disease the surgery told me to come in and collect my prescription and when i did they said it was for Lyme disease. I asked to speak to a doctor about it, but unfortunately wasnt able to speak to them for a few days after getting the diagnosis and very little information was given to me by the doctor when we spoke they asked if i wanted a leaflet! As i wasn't sure what Lyme disease was I'd looked into after receiving the diagnosis but before speaking to the doctor so i didn't feel i needed a brochure i wanted to speak to a medical professional who understood the disease especially to explain the position regarding Lyme disease as its a pretty controversial and complex disease, especially when you've never heard of it before. I was given 3 weeks of doxycycline, during which i was often tired and found it difficult to concentrate and felt other symptoms. When symptoms recurred after I finished my 3 weeks on doxy, i returned to my GP. I've since had blood tests, been sent for an abdominal ultrasound scan, and referred to my local infectious disease specialist. My GP isn't an expert on Lyme they know little about it. It took me a year and about 7 GP visits to get diagnosed. Since being diagnosed I'm not clear on the treatment i should be receiving. I haven't been tested for any coinfections and i continue to experience symptoms such as fatigue, heavy perspiration, lack of concentration. Despite the positive Lyme test, i still feel like doctors do not understand what is wrong with me. I can understand why many Lyme patients feel they have to be their own doctor. I am not a healthcare professional, and i have always (and continue

to) follow the advice of my doctor, however, to date i feel that i have not spoken with a medical professional who understands Lyme disease, its symptoms, and its treatment.

Bedridden for 4 years

I had the EM rash for 8-10 weeks and a GP who couldn't find out what it was, even after looking in books and online. In retrospect that was frightening that he couldn't find that information when only 10 miles from Thetford Forest. However when it was identified EVERYONE in that surgery were called to look. After 8 weeks on Doxycycline all symptoms disappeared, I was very lucky.

However in 2010/11 my right knee began to ache. It got worse until 2012 when I was in agony, but by now I had moved house so was registered at a different surgery where past medical records were not easily referred to. I still didn't link the possible arthritis with LD. AFTER 6 months pain, physio and painkillers, I had an MRI scan which showed the damage. 3 months later I had my first Arthroscopy 2 months following this I had stiff aching neck and problems with my eyesight. This was when I realised I probably have Lyme Arthritis.

I now walk slowly, can't run or rush, I have difficulty going up and down stairs. I can't sit on the floor with children anymore. I can no longer go kayaking and cannot sail a dinghy my favourite sports.

I have since had a biopsy on my knee cartilage & fluid which showed the following:

1. burgdorferi IgG/ M (C6 EIA) : POSITIVE
2. burgdorferi IgG Lineblot : Negative
3. burgdorferi IgM Lineblot : Negative

I still worry that there may be LD bacterial 'hiding' in my body and worry that I will get Dementia as get older (I am now 68). Some signs are that I often have to think hard to remember occasional words ... I had to remember the word dementia just now!

It's a daily struggle financially, physically, etc and I live in fear of the future

Forced to retire early due to ill health from Lyme. Expected to work for many more years in consultancy capacity with high earning power (highest of my lifetime). This has been denied me.

Savings severely depleted as paying for treatment in US.

Pensions being used for treatment not for pleasure.

Can no longer exercise having been very active including running, hill walking.

Restricted to where I can travel due to suppressed immune system.

Afraid to travel without access to my ABs and ready contact with my Lyme doctor.

Very nervous of going anywhere that ticks may be present.

Suffer from depression which was previously never a problem.

Nervous of many situations/places as I feel threatened and also feel weak and unable to defend myself.

Can no longer tolerate cold climates which I used to love.

I suspect it has changed my entire life to be honest. I suspect I was born with it and this may now explain the myriad of health issues I have had since I was about 16.

I have joint problems with an ankle which will not heal after a very standard operation.

This means that aged 41 I now can't do any exercise, which used to be the love of my life.

I am losing teeth hand over fist despite an immaculate diet and dental care.

I struggle to concentrate and remember things, and feel far more exhausted than my peers. I was a real highflier in terms of degree and early career but have now had to accept that I can only work parttime.

I have extreme food allergies and chemical intolerances which make existing in a normal modern setting quite difficult.

I have severe mood swings due to hormonal fluctuations, which again can be caused by the effect of Lyme on the Hypothalamus pituitary axis.

I am only 40 caught Lyme in 2009 I had a great business , great social life , health, energy I have none of those things now. I am still self employed but my business struggles I have to be self employed as a lot of days I can't do much it is really difficult to stay cheerful with no help from the nhs my GP just literally rolls their eyes if I mention Lyme .

I could only just go to work in the go's. I was in a lot of pain and could only walk if I was next to a wall, holding on. I'm my early 20's with no NHS diagnosis and thinking every day that I woke up, was another day alive. I really didn't expect to live very long. My Dad once said to me, "Suicide is never worth it" and it had never entered my mind, but I knew what he was thinking. He was right... I now live a normal life after taking 2 years of antibiotics.

I have had hallucinations and temporary blindness in one eye amongst other things happen to me. All of which have resolved with high dose, long term antibiotics.

I've been financially ruined by Lyme disease. I've had to pay to see Lyme specialists privately as the NHS ID consultant didn't know anything about Lyme and only gave me 2 weeks of antibiotics. Also paid to see thyroid specialists prior to finding out about Lyme. I've had to pay for private prescriptions, vit and min supplements to deal with massive deficiencies caused by Lyme. In addition I became very allergic to certain foods after contracting Lyme so that has greatly increased our food bill.

I've lost money as I was off sick for 5 months and I've since had my hours reduced and I'm told I will have my hours further reduced in September. I am now seeing improvement in my health after 10 months of multi antibiotics, so I'm starting to be able to live a bit more outside of work and sleep. I've got heavily into debt to achieve this and I'm now looking at remortgaging the house to clear my health debt whilst the further reduced hours and wage looms in my future. Financially very bleak, Healthwise finally going in the right direction.

My life has fallen apart. I was a full time teacher, doing well, happy, with 2 small children. I am now only able to work 2 half days and financially we are stuffed. I still get very tired and can't move after a couple of hours teaching.

Lyme disease has ruined my life. I have had to stop work. It has effected my family and friends through my illness. Because I had to get diagnosed privately as NHS blood test didn't work. I have spent thousands, but now no money left and still ill.

Was a regular 4 times a week tennis player pre Lyme. Am back playing but nerve damage to legs make it difficult to run or even walk sometimes. Can still get fatigued quite quickly.

Had to drop out of school at 16, had been accepted for uni. But to ill to ever complete qualifications, friends have all gone to uni I am 23 now and never been able to work, study. Isolated as all my friends have moved away for uni then work . I cannot participate in a social life as I get exhausted can't cope with noise, light etc dependent on my mum to take me out help me. I don't have a career, a social life and my family are wonderful in supporting me but they get exhausted to especially my mum as a single parent who has limited support as my brother and sister are away from home working. Finances are stretched as my mum works long hours to cover my costs I can't do it on benefits and I get really worried about her health.

I went from riding my bike on a daily basis and from walking up Snowdon to being unable to walk to the end of the drive within the course of 3 weeks. I had seizures, headaches, back ache, light sensivity, noise sensitivity and could not get out of bed. Knowing I had had a tick bite, I knew it was Lyme Disease or a coinfection (I did not know much about it at the time), I knew a little which meant I could ask the NHS to treat me with some antibiotics, and after seeing 4 different GP's at the time, was

eventually given some. They speculated I had Lyme Disease and Anaplasma, Southampton Labs looked at my case. I took the antibiotics, but I was not better, I could barely feed myself, yet the GP said there was nothing more he could do, and I had to return to normal life, he was putting it down to a virus and he would return me to work on a phased return.

I improved and went back to work as advised, I struggled through, coming home from work and sleeping, unable to socialise and having no energy for any of the things I used to. I would struggle with wayfinding, words and talking, walking and many of the things one takes for granted.

My life has never been the same since that nymph tick bite, which struck me on holiday in Dorset, from being stupid enough to sit in a field home to cattle. Having previously worked at a senior managerial level, I subsequently had to reduce my hours and take a role at a lower grade just to cope. I am doing a lot better now, but I am still not right.

Two years of persistent 'pestering' with an NHS ID consultant meant I was given 1 month IV antibiotics which, matched with my self treatment (privately buying antibiotics to pulse dose) have made a huge difference to quality of life. I am now 80% better after nearly 5 years of fighting. And I consider myself one of the 'lucky ones'.

Half my childhood was lost to undiagnosed Lyme Disease. I was unable to go to school or lead a normal life. I missed the equivalent of five years of school. I lost all my friends. It had a massive impact on my life

I can no longer function normal. Bed ridden for last 3 weeks. Had to give up all sports over last 3 years and university studies.

Loss of mobility i am in a wheelchair in bed more hours in day than up I have 50 syptoms Hubby is my carer. Severe muscle weakness in arms and legsHubby cuts my food up cooks my meals washes my cloths does all shopping Washes my hair Helps me wit pewrsonal care A mug of tea is to heavy to lift use paper cups. Used to like going to

aerobics and the gym. Unable to work have a social life, I lie in my bed in a my brain feels spaced out and drunk with exhaustion. My speech gets garbled My eyes look half asleep Diffuculty focusing and dizzy THE daylight i do not tolertate light of tv or laptop The letters go bli=ued AS my brain fatigue levels rise. I lie with curtains shut Shivering and chills running up down my body Like permanent flue I do this fully clothed even in summer It is horrible I also have terrible stomack problems bours of dioreah can be on loo 30 times a day It either that or i am on off dont move. pain wind I cant eat fruit veg salads all this makes it worse I do not like being well overweight I can not diet due to stromack syptoms all weightwwatcher meals sauces ect go through me, Colonoscopy was n ormal This started after infecredc with lymes I have senory parasia burning numbness in all muscles groups and face and head cold creeoing sensation up my saoine and back of my head f chronic pain shsrp shooting pain burning that travels up down muscle either side of body Painfull jpoints iregular hesrt rtyhm tackyycardia skipped beats extra beats isolated beats arthmias.light intoerance heat intoerance my bodyy feels so weak its sining through the floor I can not sit in my power chair for any long periods I have to lie in bed flsat out to suport my legs They tremble shake with weakness,in my wheelchair.I have 50 sytpm Cant see now or id list them all. Anyway i hate being unable to do anything Being in bed doing nothing with my life.I am angry at the nhs. i had the bullseye rash in 2006 fluelike ilnees I was gave a cream fior the rash. Asked if i saw a tick as i did not it went untreated. A ilness developed withy graudual loss of mobilty I ran a lymes testr at the gp I was told it was negative. I also saw id and neurology neurology asked looking at my syptoms list if i had had a lymes test As i had And told him negstive He gave me a Me diagnosis He could have lookede bavck 6 months and saw a western blott positve If he bothered. Id ran 2 other lymes tests he wrote saying were negative for borrelkia I have these letters on me. I then saw neurology 2 half years alter By this time its 4 years after being infected untreated and using mobility aids mobility scootor and using wheelchair in doors. Neurologisat she looked back my medical recorfs uncovered 3 western blott positves She called my mobilie to say i was given the wrong rewsults by id. I was positve 3 times

not negative I saw this Id again he gave me 100md doxy for 28days 1 pill day Tested me after this course bloods still positive Refused more doxy. OI have in writing his letter to neurologist saying there is no way of knowing if lymes caused my illness or disability as there is no diagnostic test What rubbish what is 4 western blott positives?Uk goov ni

ce guidelines state elisa is first stage test western blott confirmation of lymes He did not order a lumbar tests despite neurological symptoms. I was not given a official lymes diagnosis buy him He even called my gp quoting the sentence i just gave you. Yet hge kept referring me to the cardiologist who was fed up He never made it clear lymes affects the heart. He told me lymes affects the heart Yet No diagnosis was givenm just positive serology I went private for lumbar test was side tracked to nhs it was sae nhs neurologist i saw who suspected lymes in 2008 so i thought hed help me however the sample lay untested for 8 weeks lost Whwn it was found it was spoiled sample lab said suboptimal supernatant I asked him to get me to see new id He referred me However i was refused THe id wrote a letter saying quoting from Us CDC guidelines seronegative can not have lymes I wrote to him giving my nhs lab positives he issued me a appointment Ordered another lumbar tests Ppromised me in writing same western blott tests as my bloods from ty years before however it was notr same tests so 2 times i tried to see if lymes was in brain fluid to see and get proper diagnosis, I had had doxy for chest infections just before these 2 this can cause a no show. I also been refused treatment by nhs of privera coinfection positives the same consultants tell my gp no. sorry cant write sentences cant see keys have to true fast or no vision at all

I'm living in hell, I'm 22 and should be at uni. This is a disgrace how we are being treated.

I have little quality of life. Unable to socialise, exercise, drive, basics aspects of living, washing dressing etc are all I am able to do. I need assistance with everything, shopping, walking.

I have used all my savings on private Lyme treatment. I am no longer able to afford to buy my own house and have no hope of ever doing so while I have to keep paying for my treatment. I should not be working but have to work full time to pay for my Lyme treatment. If I don't receive treatment I believe I will die or develop severe cardiac complications. I am not able to start a family because of the disease. It has totally ruined my life.

I am currently operating at 30% of my capacity as a human being.

I have gut issues and constant fatigue.

I do not exercise as much as I used to .

No running or playing football.

I have lost confidence and find it hard to make decisions.

This is primarily a physical illness that leads to mental , nervous , emotional issues .

Very tired , sore legs/ ankles , feet and big toe which makes it hard to do my building job.

I was depressed because I kept being told that I had ME and I knew I didn't and it was along time before tested and received positive lymes test even then was sent to ME specialist! I also had positive test for Epstein Barr virus and have had glandular fever at some stage so don't know which problem in which order but felt ill for along time. I was diagnosed a few years ago and now I know if I get tired or stressed I get same symptoms back but am lucky that I don't have to work so I can manage it easily would not cope so well if I had to work full time.

Struggling to keep head above water single mother, selfemployed and paying for own treatment. Have lost £30k each of last 2 years because unable to work as many days. Unable to work for 3 months unable to claim any sickness benefits as self employed.

Unable to pay into pension for last 2 years because less income. Private Health insurance invalid because I don't have a positive NHS test, although I have a positive Igenex WB and typical Lyme symptoms. Has had an effect of my sons unable to be mother I'd like to be for many months.

Life is a constant struggle I am failing in school (6th form) due to excessive sleeping and fatigue

I lost my job as a teacher, I almost lost my marriage, I tried to take my own life, all because I was basically told I was a hypochondriac.

I have lost so much. Friends and family disappear. Phone calls non existent. Can't work but my paraplegic husband and I muddle through each day with no outside help. He gets benefits...I do not...the DWP don't believe two people in a household can function the way we have to. I can't work anymore...I am so unreliable...some days I probably could but never know from day to day how I will be. The garden I once cherished us now an eyesore. We once had goats (we gave an acre paddock) for twenty years but sadly could not care for them so as they all died naturally we did not replace, we were active healthy people despite my husbands disability...now each day is a battle...choosing which to spend our limited energies upon. I wouldn't wish thus on anyone...except for the love my husband and I have for each other...that I wish on everyone. ?

My quality of life is virtually nonexistent. I am bedridden and have been for the last nearly 10 years. I have been ill for 20 years. I am in terrible pain which is neuropathic and comes from damage to the nervous system. I have too many symptoms to write down. I have no social life and have not been able to work for nearly 20 years. It affects my husband and young son greatly as we can not go out as a family and all my son has ever known is an ill mother.

It is a whole family thing. I am exhausted. My kids are ill and my husband incapacitated. I would love more flexibility and fitness so that I can climb mountains, walk the world and do the things I used to do. But instead I look after sick people and feel sick and discarded by the NHS myself. The expense of usa medical care is debilitating to us as I also have to be the breadwinner and the money spent would buy marvelous holidays and better accommodation.

I have had odd symptoms for the past 15 years, but as they came and went noone took them seriously or said I just have to live with them. These included GI problems and anxiety, memory problems as well as strange blood results, etc. In recent years I have developed severe comprehension/concentration/memory problems, OCD type of symptoms and intolerance to noise so found it impossible to work in a hectic environment, and so I had to give it up.

Increased tiredness leads to lack of energy for running etc. Also ears affected, so not sociable in loud company or concerts etc.

I have had to give up my full time work in my own business, I have had to sell our home and move the family to a cheaper home closer to my parents so that they could help us with childcare enabling both my wife and I to work. Prior to this I had to accept 6 months of my extended family paying our mortgage until we realised I wasn't going to get better quickly and changed our circumstances. I now choose to have a very limited social life in order to have enough energy to do part time work and only leave the house when necessary. I have had to travel to Germany to find a doctor to treat me and have only been able to afford this through financial support from both my parentsinlaw and my parents. My life is unrecognisable compared to 3 years ago.

Lyme disease has affected every area of my life. As a graduate, I had a bright future ahead of me with a career in London lined up which I was never able to start. Due to interruptions in my education due to this illness and subsequent relapses, I have lost 10 years of earning power and I am not a contributing member of society. Instead of earning a good salary, I am dependent on my parents and minimal benefits which would be impossible to live on. I am unable to socialise, drive work or fulfill my dreams and ambitions. My days are filled with pain, neurological symptoms, vision problems and cognitive dysfunction. I don't feel safe in my body.

My life is affected on a daily basis.

I don't Pursue any longer because it gets me down.

Devastating! I was a qualified nurse, highly qualified aromatherapist and reflexologist. I also taught aromatherapy at my local college. I am intelligent and now feel useless and an invalid person. I have not been able to work since 1995, I was not retired on the grounds of ill health but have never been able to go back. Husband eventually went bankrupt because of looking after me and my three children grown up now don't remember me being well. My GP at the beginning diagnosed me and could not get anyone to help me in my treatment to give him advice. Because of this I had one week of antibiotics and weeks of steroids which I know now was the worst thing I could have had. One consultant said no don't give her anymore antibiotics wait and see! Now we are having to sell the family home because my husband is 65 and our financial plans are no longer valid and we can't pay off the mortgage. The stress we are living with is horrendous. I feel guilty that I am not the wife and partner I would have been. I feel sorry for my husband who had to try and hold everything together. I have no quality of life and manage to get dressed about once a week. I have to decide each day do I shower or try to clean up I can't do both and more often than not don't do either. I go to see my mum who is 98 and the day after I can not do anything. I can't walk my

dog which I loved and most of my hobbies of the past are not appropriate now. Hiking, camping, barbecues etc.

mobility, housebound, photophobia, loneliness lost friends, constant pain and agony, clothes don't fit due to increase in weight, have problems getting dressed, problems cooking, problems shopping, I do not have any social life or visitors, problems travelling on any journeys even a short journey, loss of concentration in writing and spelling writing words back to front also loss of arithmetic skills, very frightened when I suffer full body tremors, no faith at all in NHS, paranoid about going in grass or plants or trees or my dog carrying ticks, suspicious of any tiny black dots incase they are a tick or nymph, lack of exercise and fresh air and general socialising with other people, feel totally hopeless and no hope of getting better

I have completed this survey for our 5 yr old Son who has Lyme Disease. He has suffered. Huge amount of joint pain and been unable to take part in normal child day to day activities like visiting the park & playing football. He has also missed sports events at School.

I have to be around incase the school call me to collect him and be free for hospital and doctors appointments. We choose to see a homeopath once a Month so have to find the extra money to pay for that and may now have no choice but to look at private treatment so are fundraising.

For the past four to five years i started to have unusual symptoms, a different 'virus' almost every two weeks and would be sent away by the doctors. then in March/April 2015 the symptoms got worse: my memory is really bad, can't concentrate, chronic fatigue, always in pain unable to do most things. I was misdiagnosed and was being 'treated' for ME/CFS which made me worse as the medication i was given to sleep at night hightened my fatigue. As a result, I basically withdrew myself from my friends and even my family, nobody understood what was going on with me, I didn't. a few

weeks ago we had to pay privately to get blood tests and the lymes blood test which confirmed i had Lymes and it cost thousands and now we are searching for treatment because the NHS won't do anything about it and refuse to admit lymes is in the UK. Lymes has basically ruined my life, i am still a student in school and i cannot complete a full day and when i do attend lessons i cant concentrate and i wont even remember what i learned in that lesson a few minutes later. I was confused for many years, and having a constant 'virus' became my normal and now that I finally have a label to all my symptoms i feel relived yet helpless knowing that the NHS, our doctors don't even know about Lymes disease. i am starting to lose my faith and hope.

Completely changed. I lost my smile and function of my face.

I get headaches and tire very easily. I am meant to be cured I am 1000 better than I was but I will never ever be me again. I forget things and studded now.

remortgage the house. Debt of £10,000

limbo.

29 years of my adult life have been devastated by Lyme disease (as I now know). Since the age of 17 I had an 'M.E' diagnosis which at my worst has seen me bed bound and barely with the strength to feed myself and totally dependant on my parents.

I was a happy, confident, energetic soul until the age of 17 when I was struck down with this frightening and cruel illness.

From NHS doctors I have in the main faced dismissal and scepticism. I did not, and do not deserve that I deserve care and a willingness to help my ill health, so that I may start to live now, at the age of 45, regain my health and realise my potential albeit with a 29 year hiatus that I can never regain my lost years.

I am a 26 year old male that is the sole provider for my wife and my 2 year old daughter. I was a successful salesman and had not been to the doctors in over 10 years.

I was left to rot after 4 weeks of single course antibiotics from the NHS just before Xmas 2014. Your infectious disease doctors refused to treat me as my symptoms were apparently "non specific" despite having a positive blood test via the NHS for Lyme and at least one other confection.

I have since spent upwards of £10,000 on treatment abroad and am FINALLY beginning to make progress after wasting 12 months trying to get the NHS to treat me.

I almost lost my job (had I not have been one of the best salesman I probably would have) I have been too ill to enjoy my now 2 year old daughter growing up.

Yet the NHS are not interested as according to their guidelines, I have had "adequate treatment for Lyme disease".

I have lost a large number of friends because I am simply not well enough to do anything active or be social.

The lack of understanding and compassion shown by the NHS is appalling, I had not used the NHS for over ten years before falling ill with Lyme disease and was treated like a hypochondriac.

stopped work, about to return

I am now 24. I have been too ill for any education since age 10. I have been roombound for the past 7 years and bedbound for the worst 2 years. The NHS treated me with CBT and graded exercise for misdiagnosed CFS it nearly killed me, I was hospitalised for 10 weeks. My father has been my fulltime carer for the past 10 years. The drop from being a two income to a one income family has dramatically effected our finances.

Everything has changed for me , I am unable to do anything I previously did at work and activities , I felt my doctors didn't listen , one doctor accused me if looking for things wrong with me as I couldn't have so many things wrong with me at once. I have been in trouble with work as I have vast amounts of time off. The specalist is now

telling me I haven't had it or got it as only part of the test came back positive , even though I had the bulls eye and 18months I went to the doctors with it , she was diagnosed with an allergic reaction at the time . But the specialist is saying I have fibromyalgia. They do not listen to me about my systems

I am unable to work so have very little money.

I have lost friends and family who find I am unreliable, can't understand my illness or symptoms and think I'm making it up.

I am unable to be sociable, I lose my words, my memory keeps failing me, I am on very restricted diet

I feel ill or the time. When I have an infection, it terrifies me I have so many symptoms and I am ill for months. I cannot go out, or get out of bed. I feel isolated and rejected as the NHS tell me I do not have Lyme and ignore my private tests.

I live alone so my symptoms seem to be increased and I don't have help

I am not the person I used to be, each year I just get worse

My life is ruined I don't go out my children have lost me as their mum I feel like I don't know them, I can't work, lost friends

Housebound, mainly

Whilst I am back at work full time it is a struggle so I have applied for a flexible early retirement down to 3 days/week. It makes a significant difference to my final pension as well as 3/5ths of my full time wage.

I was previously extremely fit and active for my age. I no longer run or cycle due to continuing joint pains. I have had to pay extra to go to gym for controlled exercise I can manage.

Significant difference in social life as too tired after work & can't drink alcohol. I struggle in busy, noisy environment and crowds. I tend to avoid people now.

Because I am self treating with herbal protocol financially this is costing £200 300 a month

Diet strict GF, dairy free, sugar free, organic has probably doubled my own food bill. It means I often eat separately from my family

I was a Marathon runner, I ran a Kick boxing school, I ran 2 companies employing 30 people together. Nowadays I am so unwell I cannot leave the house for days upon end, I visited a Dr Boucher (a Lyme literate medical Doctor) in Brussels who tested and examined me and confirmed that I have been suffering from not only Lyme disease but Barbitis, Candida and even worms (god forbid), along with several other coinfections. He prescribed the ILAD (You should know this) regime which I have recently started, he has treated and cured a lot of people with Lyme using this regime. I am very unwell currently but that is to be expected.

It has been devastating. I was 42 yrs when I became ill with 3 children aged 2, 6 and 10. My husband had to support us financially as I have been too ill to work ever since. My family life was affected very seriously. I had to employ child carers and cleaners, then I used a nursery. I was bedridden for much of the time and I could not be the mother I wanted to be and I think the effect on my children has been substantial. It placed a heavy burden on my husband and I was unable to do family things. I have been mainly housebound and cannot walk far therefore have to use a wheelchair on rare occasions I go out. I struggled to keep up with friends and relatives during better periods but mostly I am unable to see people as I feel too ill. To be honest it's been a nightmare as ME, my original diagnosis, was not taken seriously and I received no NHS help. I was forced to go privately for help which was costly. To be fair the NHS agreed to some of the help including B12 injections and magnesium injections. After the Lyme diagnosis I was given help by a private doctor, including antibiotic protocols and help with supplements. The NHS supplied the core antibiotics. I did improve a lot but the private doctor was hounded by the GMC until he retired. I subsequently relapsed and have

been too ill to travel anywhere to get proper help for my Lyme Disease and multiple Coinfections and viruses which continue to plague me.

Lyme disease has affected every aspect of my life for the last 18 years. It gave me chronic neuropathic pain, fatigue, poor memory, and brain fog. Depression could be from being sick for so long or from the Lyme. I was 32 years old when I first noticed something was wrong. I didn't see a tick or a rash that summer but I do remember that I felt like I had the flu for a few days. I gradually got worse. I started getting headaches and migraines every week. My feet became painful, especially the soles. Eventually I had to give up on wearing shoes altogether. I can only tolerate fur lined sheepskin boots with a good sole. I sleep with ice on my back every night. I was a young mother of 3 children who enjoyed walking, running, skiing, and water skiing. My life as I knew it is gone. As I write this my arms are burning. Sometimes my nerve pain is only relieved by being asleep. I am always aware of my pain. I have become good at faking being well in order to have some sort of normal life and for the sake of my husband and children. I love them very much. I beg for officials to investigate what is going on with this debilitating disease. Why is public health so quiet about Lyme disease? It now meets the definition of a pandemic. Yet we hear nothing from the very people sworn to protect us. This seems very strange to me. Why is this so?

Thank you from,

Desperate

No life at all can't walk very lonely

I'm constantly drained, dizzy spells but not serious enough to affect driving.

Worse irritability and frustration which is made worse by not being able to absorb data and recall.

Headaches and trouble sleeping

Tremors and random pains(lower back) nausea and random air starvation whilst sleeping.etc etc etc

Lyme has affected lots of areas of my life. I was diagnosed with ME when I was 15 I became reclusive and exhausted to the point where I was able to complete one A level. For a small period of time I felt a little better so I went to university to do an art and design foundation. However I pushed my ability to cope so much that at the end of the year I crashed with flu like symptoms, funny vision and tingling pain in my legs. I visited my GP four times and each time I was told I had flu. Finally I started to get dizzy when I stood up and eventually fainted. Because I hit my head my mother insisted I be taken to hospital for examination. It transpired I had dangerously low sodium. The Drs said this was because I was taking Citalopram (prescribed by my GP), but as my sodium level slowly corrected its self, I lost sensation in all my body. The Drs at the hospital didn't believe me, so I was forced to try and stand. Of course my legs were like jelly so I fell, pulling my catheter out in the process! I was humiliated. They later diagnosed me with GBS, because of my illness I had to give up my three year degree at university. Later my boyfriend and I had to end our relationship. I moved in with my dad because he had wheelchair access. I could not bath myself, go to the toilet by myself or sleep properly. I vomited for about 6 months, to the point where I was nearly admitted to hospital for low weight. I had loads of investigations and was told I had a Lupus like syndrome and psychogenic vomiting. As my ability to walk improved I developed a phobia of being around people. I became paranoid and depressed, making socialising hard. I have now become reclusive and panic in crowed places. I am now 22, but I can not enjoy life in the same way my peers do. 2 months ago I was privately diagnosed with lyme disease and am starting the long process of treatment. Lyme has ruined my life and affected every area of it, however my support system of family and friends has made the process more bareable and I dread to think how others cope with out this. My mum passed away during the period of my recovery. I was unable to care for her and our relationship was affected, because we were both so ill! She didnt see me better

and I will never forget that. My financial support from the government did not appear for a very long time, I was denied what was DLA, even though I was incapable of walking, dressing and bathing! Luckily my father was in a financial position to support me. What upsets me the most is how difficult the whole application of benefits was and the lack of support in aiding me in this process. I hope that no one else has to go without financial independence especially as illness takes independence away from all other areas of life!

Dropped out of uni, later dropped out of college, unable to work for 3 years or do anything else really, at some time even including to go for a walk, unable to work fulltime for the next 7 or so. Not had children because it wouldn't have been fair on the child. Not got a big circle of friends as for many years wasn't well enough to socialise or have any energy to do anything, had to use weekends to recover to be fit for work again... Finally able to work fulltime again for the last 3, due to treating myself with antibiotics intermittently, but still relapse when I am off them for long (a few months). Obviously due to this have lost about 10 years of proper earnings and pension contributions and never been able to buy a house.

not able to work so financially affected. relationship struggles due to not being able to do anything. Family issues and upsets. No social life so lost touch with any friends very isolated now

It has destroyed my life, come to have an active life and professional life thrives, to live in the hospital and at home

When I fell ill in 2011 and not diagnosed until 2013, it was very hard. Lyme Disease had an impact on family life, social life. work and financial. I also felt isolated and lonely. I am determined to not be there again but it's hard when the pain has returned or I find it difficult to walk!! If I have no joy with the NHS, it looks like I may have to go private

again as I don't want to give my job up again and I won't!! My neurologist thinks it maybe what I'm left with but I find this odd seeing as symptoms have flared up since last summer and my last results were positive.

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Every aspect. Career, social, financial. I feel unable to achieve my full potential.

I was the fittest 30 year old around. Great physique, playing sports and never visited a doctor or hospital in my life. After the tick bite I have had a steady decline in my health. All the major symptoms associated with Lyme including the ones that make it hard to function in daily life such as memory loss, poor hearing, brain fog and nerve related problems. I think I am doing my best but I know my body is only running at 50% at best. Through misdiagnosis I am definitely one of the candidates who have cost the NHS a small fortune.

From a full time special needs teacher and half marathon runner to often not being able to get out of bed. If u go out at all, it's a big deal and I often have to cut it short. In wheelchair whenever not at home.

Can't work. Holidays cancelled.

it has totally destroyed my quality of life ..

I am existing rather than living. Every part of my life has been torn apart by this disease family, career, relationships, enjoyment and ability to plan a future.

I have been ill for five years, unable to go to university. Unable to work. Lost a lot of my friends. I have to rely on my family to support me with everything, cooking, laundry, taking me to doctors appointments, money(my parents give me an allowance) It has caused distress for my wider family too such as grandparents who hate to see me living like this. My relationship with my boyfriend has also broken down too. I hardly ever leave the house , when I do I have to use a wheelchair. At the moment I spend most of the day in bed and find it tiring to even eat or drink.

Constant exhaustion, even though I sleep over 9 hours every day, an average of 14 hours of sleep every day. Lack the energy to work even part time as I am ill day in, day out. Lack the energy to have any social life. Symptoms show no sign of improving, my health keeps on worsening and I'm not even 30 yet.

Serious debt, father has nothing to do with me, had no children my 20s and 30s destroyed. No partner as just too sick

I can't walk more than a few feet at a time. My days and nights are spent between bed and couch. I live with enormous pain. I no longer have friends call in. My mum is my carer and our world comprises of us, our puppy, dr visits. That's it.....

I work 4 hour days, under supervision from occupational health at work

My personality has changed...

I was infected by tick bites in 1985. The disease affected every part of my thinking, every part of my brain, and the pain levels varied from constant aches to the level

described as excruciating but I was able to fight it for 5 years before I lost my ability to work ever again.

I lost my career, my marriage and all of the friendships with work colleagues and in my social life outside work too. I'd just completed my MSc and was coauthor of 7 peer reviewed papers in the field of neurochemistry and neuroanatomy. I'd been working full time but doing my MSc research in my own time and spare moments at work. My family were kind and helped me financially after I had had to sell the house I'd bought after my divorce, but they couldn't understand the illness, and I missed being able to visit my brothers and to see my nephews growing up.

I sold my house to move near to one of my brothers, because all the doctors said my "ME" would get better with less stress so I moved to the seaside. By then I was a single parent.

The years of poverty, with only the state Incapacity Benefit to live on, have been heartbreaking, not because of my own lack of material things, but because my child was one of the poorest in his class, yet one of the very brightest. As I got more ill and disabled, I was awarded Disability Living Allowance, but by then I was too ill to take my son anywhere, and he has really missed out on things like holidays, going swimming, even joining in the local football teams we were isolated socially from our real peer group. and not accepted properly by the council hose estate peer group, if that makes sense...

He achieved many A* A levels, and should have attempted Oxbridge entrance, but that never happened. How could we even afford the train fares for him to go to interviews?

he had to choose a university near to home, and it wasn't the best, and didn't do his preferred degree options. It's things like this that make me so sad, that my illness, which was dismissed as merely ME, then labelled in the late 1990s as CFS, and denigrated as a weakness of will or personality until I began to become more unable to walk it's this that makes me so sad, that my life was ruined and my son's life could have been so much better.

Very poor quality life. Unable to do much. Fatigue easily, bad headaches, trouble concentrating. Rashes. Poor circulation. Pain in legs. Stretch marks but no weight change bartonella.

Severely affected my entire career & my relationship. I now live alone

I am a 16 year old student. I manage a reduced number of GCSEs by sleeping a minimum of 12 to 16 hours a night. I can't socialise, exercise or reach my full potential. My joints and muscles ache, I get random pains and a fuzzy head and this is when I am doing well. I am 16 and feel like I'm go.

I have lost almost everything and am forced to move to USA. I am devastated to leave my country and my family.

My daughter was just 3 years old when I started to get ill. I only have the one child and won't have any more due to my illness. Four years on and I feel robbed that I haven't been the mother I longed to be!! I have totally lost faith in the NHS and I am sick of being told that I need antidepressants even though I have a long list of symptoms apparently I'm just depressed and because my MRI ,s and all the blood tests etc come back negative the ruematologist no longer wants to see me as he doesn't know what to do with me! He doesn't acknowledge the lyme test I had done in America which was positive as the two NHS lyme tests came back negative! I have totally give up!! I can now only work 2 days and have had to put my 'family home' on the market as I can no longer afford to live there. Me and my partner of 20 years are on the verge of splitting up because of the financial, emotional and physical stress. How can one day someone be full of life, happy and content then overnight be so ill and yet be made to feel your lying or making it all up to the medical world. These doctors need to do there research and major training on this dreadful disease!!!!

Everything has changed, and PTSD has also now been acquired.

I don't have any energy to take care of my family. I barely get through every day because of pain, fatigue and depression. Working even part time is hard and financially my whole family has suffered. My social life is nonexistent now. There is no energy for anything. There is stress in my relationship because of my low libido and personality changes.

In a nursing home at 31 yrs old ive lost everyone n everything a paraplegic n disabled been in 18 major life support comas dying

Until I got the bulls eye rash and diagnosis of Lymes disease,6yrs ago I had a good quality of life.I saw an Infectious Disease consultant who sent an ELISA blood test away to Porton Down but came back negative.I have seen 9different consultants who can treat the symptoms but will not accept that all the symptoms are connected.The GP has asked the Microbiologist if I can have a long course of suitable antibiotics but it was declined.This Spirochete is very difficult to eradicate and N.H.E.should allow GPs to use a clinical diagnosis not just the results of an unreliable blood test.

My quality of life has been affected greatly in the last 8 years. The NHS were unable to offer an explanation for my chronic fatigue, joint pain and headaches unfortunately their Lyme Test proved negative. In desperation I went privately to the Breakspear Clinic in Hemel Hempstead and after testing, received a positive Lyme diagnosis. They prescribed a variety of ABX which thankfully my GP agreed to prescribe on the NHS for 6 months. The ABX had limited effect but various vitamin supplements etc. (not available on NHS) improved my quality of life and eased some of the fatigue symptoms. I continue to take these supplements which cost a considerable sum and are a great strain on my finances, I am 60 and unable to draw my state pension until

age 67. I am just able to cope as long as I pace myself, but suffer from ongoing joint pain, poor balance, poor memory and concentration. The Breakspear Clinic, after food allergy testing, suggested I follow a glutenfree diet which has also helped. I perform Perrin Technique Lymph massage and body brushing every morning, in fact I'll try anything that is reputed to help!

Not being able to concentrate in my job lack of energy to do my job or any sporting hobbies

Lymes CFS and ME not classified as an cronic condition and the length of time from presenting to medical help

My life has been devastated by getting Lyme Disease; I have lost my career, independence, confidence, friends and at times my own sanity.

Higher costs in heating/electric, had to buy supports, braces, walking sticks, special tools like jar , bottle, can openers, support socks or edema in legs/feet even on waking. Heat pads, tens machine.

Had to quit showing animals and give up 95%, give up allotment plot, can't manage a holiday, difgicult to plan things, missed family occasions, from anniversaries, birthdays, funeral and a wedding due to Lyme flare. Lost 'friends' and some family don't call, since I can't help them out, they won't help us out (hubby has heart damage, got sick within months of me getting a tick bite in 2008 (he wasnt in same place as i when got bit.....) and he often shows certain lyme symptoms in cycles and cycling hot/cold flushes (not usual in a slim man!) With both off us signed off from being able to work, we get roughly 1/2 the income would do if was still working and fibd we have greater outlay because of disability needs, then travel expenses. Heating on all day, now ill, yet when worked, heating only on morning 2hours and few hours of evening, just before got home to just before bed.. roughly extra 1012 hours heating a day. Now at home, TV/computer/radio/kettle/cooker/microwave on more, didn't need when

working as not home. Need to use taxis often, as can't drive or afford a car. Stuck in less than suitable property, as stairs to front door but no money to move. Feel cut off from life, want to work, but as condition left misdiagnosed for years, left that unlikely, as no one would employ someone who can't guarantee when could do some work, how long for, when again after a flare, employers can't be expected to employ someone whose conditions makes them unreliable.

The pain can be very severe, so get housebound

Cause its lyme, I have been treated badly, as if faking things, have had to really push and explain in depth, that a "good day" doesn't mean NO symptoms and NO pain, a good day is like gold dust and liken to a day a well working person would take off work because they feel just a bit too sick to drag themselves to work (worse than a workers duvet day!) But benefits assessor's almost deliberately miss interpret and make you feel like your having to beg for the support your entitled to. All has a negative and stressful effect on health and I'm sure slows and sets back healing.

We can't afford a car, holidays, new kitchen (ours is 30+yrs old!), get someone to decorate and can't manage it ourselves like used to do before lyme.

The increase in money needed to go on medical equipment or other treatments, costs getting to appointments, having to pay for gluten free diet (as gluten free products, be they actual gluten free version or just the standard brand that uses a none gluten cheap filler, often are more expensive, takes money from savings, so when say cooker, washing machine, fridge etc breaks down, its difficult to afford another and you can just do some over time or take on a part time weekend/evening job to cover these sudden expenses. Banks less likely to offer loans....

Financial worries can lead to worsening symptoms and slow healing too.

I have had to give up many hobbies and interests since Lyme disease caused arthritis and neuro and eye problems. My life quality dropped to about 25% of normal on average and after four years of treatment has gained roughly 20% back of what was lost by time diagnosed, slowed by many stressors and poor attitudes to someone with lyme.

My life was turned upside down after I was bitten 6 years ago as i was very fit well and cycling etc to keep fit and had never been to the doctors ever till this point. Then some weeks after the bite I got I started feeling unwell and dizzy and breathless and tired and generally week and doctor done checks and I told him about the bite while I was camping by the woodland in Wales and he said I had all the Signes of lymes desease and I remember the bite very well. He then put me on 2 weeks of anti biotics and said I should feel better but it was about a month down the line by the time I started them. I have not got better and me and my wife and kids have gone through some really tuff times with me being so unwell that I've had to take so much time from my business so money was tight and I was battling my symptoms every day at work and my vision so affected I could hardly see at times and so week and annoyed that the doctors would not help me anymore as they said I've had my anti biotics and should be well and it's all in my head now and tried to put me on beta blockers which I would not do as I would rather battle on without stuff like that. My kids have had to watch me go from a fit and well man to a broken man who some days couldn't even get off the couch or go to work or even speak at times. I am now starting to get my life on track with alternative treatments as I won't ever go back to the doctors to be insulted in the way they have insulted me and not listened and helped. The treatment and things I have to pay for can cost a bit but money is nothing if your not well enough to enjoy it and I am starting to improve over the last 12 months but still got a way to go before I'm back to my old self but atleast now my kids are not watching me unable to lead a normal life and I can do more with them and my wife of course who has been my rock through out everything. I've been lucky in that way. Wouldn't wish lymes on any one as it has taken some years of my life through such a small tick bite. I wish all lymes patients a good recovery

I was 25 when first diagnosed and as you can imagine at that age my social life was destroyed. In fact my whole life was destroyed. I didn't work for 6 years. I was

bedridden for a year and a half, and in heavy treatment for 5 years. I have received nothing from the NHS other than antidepressants, pain management clinic and sessions with a psychiatrist. I was at a point of being unable to read and write, in constant debilitating pain and exhaustion with a huge variety of symptoms. I thought I was going to die, no one took me seriously! I was living the life of an 80 year old in the way I walked and things I was capable of doing.

My parents took me to a private hospital in Hemel Hempstead that I believe saved my life. It has cost them thousands. I am now in a position to work part time and have gone on to have 2 healthy children. My life still takes a slower pace, but my quality of life has improved. Yes I still suffer pain and take supplements but I am able to get out of bed each day and have a smile on my face (most days). This disease is so detrimental and I've seen it so many times, the NHS need to wake up and offer more to those whose suffer. I believe so many people with MS, ME, Fibromyalgia, CFS, and other conditions all have Lyme disease. When will people realise and help the suffering!!

My life has been completely destroyed by this illness

Lyme has destroyed my dreams. I became ill just before my 19th birthday. I had just started studying at one of the top fashion universities in the world. Within months I was sleeping 22 hours a day and unable to continue. I was diagnosed with ME in 2010 since then I need my mother 65 to look after me, take me to appointments and now wash my hair. My social life, family life, relationships and job prospects have all suffered drastically. I was a hard working, ambitious girl. I've not been well enough to work for 6 years. My situation has made me feel like death would be a better option at times.

Ruined my life

I went from been an extremely fit soldier with everything to live for. Then i was bitten by a tick, which subsequently destroyed my life completely, one year after that I was diagnosed with Lyme, given a short course of antibiotics, which did not improve my health (longer courses have helped me), one year after the diagnosis I was medically discharged and left with no help from the army. After using my savings on private healthcare, I was able to get proof of my disability and fight the MOD in a tribunal, in which I won, however due to how the pension system worked, I was only able to attain the smallest pension available. Its nowhere near the amount I was used to earning or living on. I have pretty much been thrown away with no help or assistance. At night I struggle to believe that this could actually happen in a civilized country.

I feel left out, abnormal life for such a young age. It is suffering and most difficult is that medical help is hard to find. It is struggle through life and no light at the end of the tunnle

Disabled. Trapped. Destroyed. Bankrupt.

Family and social life has changed

I have no joy anymore. I am sick 24 hrs a day.

I'm in constant pain and have scary neurological symptoms. I have a four year old boy and husband i need to get well for and start enjoying my life again.

I constantly live through waves of illness, pain and symptoms and so I have had to choose what to expend my energies on. I work part time and this means i have to prioritise work. Socialising, events, shopping and my poor husband often suffer as I have to rest often.

Pain, fatigue, confusion, memory loss

I spend 95% of my time in bed, I have lost a lot of friends, I have strained relationship with most of my family and causes a lot of stress and they treat me very badly making my condition worse, I can't partake in any activities that would contribute to the career I dream of, I have to travel miles for appointments that give me any sort of help, the closest being 40mins away and I have to pay for privately. Majority of my money is spent on extra medications and things to try and stop my health from deteriorating further.

As a result of becoming ill in my early teens, I lost most of my teens and all my 20s to it. I'm trying to claw back a life in my 30s. I've had no career, have no partner or children.

Have paid thousands in absence of proper treatment and consultant knowledge

Bad! (Sorry My english is NOT good.....)

My son was 7 years old when he contracted Lyme. I got him treated within 10 days of the rash appearing. Hard work to get him treated, he had a positive blood result. My son basically didn't go to school for a year all day he was far too tired. He is well at the moment and physically fit just completed a bleep test. One thing I was told was to keep him active, the last 9 years his feet have not touched the ground. He is playing county cricket so very active.

I am bedridden...

My story? I wish I could express in words the importance of this to everyone. I think if you were living it you'd understand. Family and friends I am living this. It will cost you nothing but time. Lyme/ Babesiosis has changed my life. I know people are dying and they don't need to be. I became sick in 2007 with a fever, rash, paralysis, Bell's palsy and a classic list of symptoms. Each and every test they gave me was negative. They

told us I had ALS. I had to leave my beloved job teaching of 25 years and I began this journey. THIS COULD BE YOU! Doctors cannot treat because of outdated guidelines and it is now in national news for a reason. I am now in my third attempt treatment wise to eradicate this disease from my body. One attempt in March, one in July, and now I am again in treatment at a more extreme level. Each has left me close to bedridden daily and unable to lead even close to a "normal" life. I now have a port and stay close to an IV as a rule. This disease is beyond explanation and the financial, emotional, neurological, and pain/physical effects are even worse. We are in an epidemic in VA and other states.

Friend and fun are going to Zero.

Its a great break in life bevor i was succesfull selfemployed and now i am only at home.

Sometime cant walk !

my eyes are getting worser

The live is slowly stopped and changed totaly !

Zero zest for life. NO energy.

There is no quality of life whatsoever, families illness untreated as Armin Lab tests deemed unreliable by GP. Brother of same age and myself have never been well and life for us is merely an existance. Mental and physical fatigue greatly impact on our abilities to live a normal life and it is a constant struggle to manage this. Our mother has diagnosis of ME and Chronic fatigue and is also extremely unwell.

We hope for the day when our illness is recognised and treated.

Lyme disease has drug me through hell. It has taken away my ability to do a lot of things. People think that it just makes you tired. They are so wrong. Lyme disease and co infections have taken over my brain as well.

I first became ill and had no idea what was going on. My Dr tested me for everything , including Lyme test by Public Health in Canada,,Everything was Normal so of course they labeled it as Nerves. I was so dizzy I could not stand up. I lost over 50 pounds and lost muscle mass ..in just a few months..but still they said it was my nerves...I finally after many tests and appointments felt I would just die anyway so I retreated to my home and thought let it happen. I went to the USA for confirmed DX of Lyme via Igenex test, had initial treatment in New York which cost out of pocket \$40,000 ..and hit the wall financially. I showed my Canadian Dr the test results and treatment plan , at which they said this was not correct , we don't have Lyme here.. Again I retreated and was on No treatment , and continued the down slide of life . That was baci in 201011. Today I am still not treated and know I am not well. I see no medical DR as they have now labeled me as Mental ..my friends and family think I am totally fine mentally BTW. I am now not even having normanl medical survellience for health care , which in itself is very bad not to have check ups etc. I cannot afford to go to the US for treatment again , as well the medical staff here won't support me if I become ill from the treatment as they don't believe in the disease. I at time as finance allows see a ND for support ..which is really less than helpful as they are unable to order labs , xrays , antibiotics etc ..and everything is out of pocket expense the patient

At this tiem I feel I need to prepear to get worse and eventually pass away. I am not the person I was not long ago..a working Registered Nurse with a degree, participating full in life..exercise , hobbies etc.

good luck with you plans

Family has spent way over £100,000 on private treatment and testing and I was bedbound for months in constant pain school was affected then had to drop out of university twice didn't see friends for months watching days pass by unable to do anything couldn't have a job

I am not able to work.I wasn't well to do anything.

From independent fit project management within nuclear industry to bedbound
Lost 16 years of earnings, refused by NHS real support funded own treatment for Lyme
and several coinfections

Lost chance of having my own family, independence, fought for benefits, care, even
basic full blood count

Disregarded, yet fought back as needed my health to be addressed

Invisible illnesses are just that, even when you are so sick neglect has played a huge
role to my overall decline

Lyme creates problems because the government are holding my cards, not because I
have it

I don't have one. I work and sleep. And feel lots of pain. Not socialised for 2 years. I
earn £75k and every penny goes on medical bills for me and my daughter, despite
paying for the NHS. I've had to sell everything inc my car and often struggle to eat if I
get her what she needs. Something not quite right there when I'm on a very healthy
income. It sickens me. But because I am, there is no help.

In every way I am nearly mostly housebound and I cannot work. It affects every area of
my life.

Since I was diagnosed at the Breakspear Clinic I am slowly getting better. I went
through a bad patch but I am now so much better. Before I couldn't bend my wrists or
fingers and now I can! It's a long long journey and it makes me sad to think if I was
correctly diagnosed I wouldn't have gone through the horrendous pain of the last 3
years. I am also on strong herbal medication which is helping.

It has completely destroyed my ability to work full time. I never know when it's going to hit me, but when it does I am unable to move initially and then unable to get up for at least 23 days after which my legs barely function for another day or so.

No independence. Too much time in bed. Been to hell and not back yet, if ever

i am feeling going to die very painfull

This disease and multilayered issues that follow lyme have been complicated and slowly self revealing. Child anxiety, sleep issues, high strep titers contribute to severe auto immune problems. Strep is also a bacteria that can get into the blood/brain! Co Infections, viral,.....joint damage, eye deterioration, mental emotional behaviors compromised. Family has been broken for some time. Many doctors, searching. No answers. Mood changes, sleep problems. Forfeited an engineering scholarship and music degree due to severe illness. Family has deteriorated emotionally, no friends, no education! Bright, cross country runner who could run 10 miles. Amazing baseball pitcher shut down. Very sad to witness and lyme patient sometimes doesn't have insight into all of this!! Something has to change!

My life has been devastated. If o can get better, I will be mid 40s at least. What then? I've lost my career already. No idea what I will do or where I will end up. Certainly not with achievements and goals I had planned to have had by now, that's for sure!

Yes it cause me to have 2 major strokes 5 years ago and I was only 31 years old . It has destroy my life this been a nightmare and I am not getting better .

I can't work, go to school, workout, lost a lot of relationships with friends and family members.

Following cat scratch from sick cat (we didn't know what ailed him but it was clearly Lyme as both my husband and two sons had illnesses related to LYme) in 1993 which infected me with Bartonella, Lyme borreliosis and Chlamydia Pneumonia, my health deteriorated alarmingly although I never connected it to the cat. I managed to stagger on at a much loved job for 14 years and to do that had to give up everything else, and eventually had to give up as I could barely walk from car park to office and needed a heater under my desk and still I had no idea what was wrong with me. I went to GP surgery every few weeks and occasionally got antibiotics which I knew made me feel a little better but no real interest was every shown to the plethora of agonising physical and neurological symptoms I was experiencing. I was fortunate to have some redundancy which helped for a few years. I then stumbled across the one and only private clinic in the UK which saved my life and I mean saved my life. I was diagnosed, tested and treated for 6 years. I received some sickness benefit but it was taken away, as the assessment doctor felt I was not ill enough to not be working. At that stage, I couldn't even do essential tasks like food shopping. I got it back on appeal and with written help from the clinic and am now on state pension with no other benefits. I could do nothing and had to give up tennis, golf, swimming and a pretty good social life. I am about 70% better following private treatment but a tick bite 18 months ago sent me downhill again. I self treat but still use the clinic when I can. The ignorance and subsequent cruelty of NHS staff is almost unbelievable. Not one doctor or specialist has ever shown me a jot of compassion when I've been in dire straits. How many times have I had to explain that the symptoms of "depression" bear no comparison with the symptoms I experienced. Its heartbreaking to meet others in a worse state than I who can't afford private treatment for themselves or their children and who get absolutely no help at all from the NHS.

Before I contracted this disease I was working I had a law degree but had been interrupted by breaking my spine at the age of 18 but continued graduated worked went to the gym cleaned my house cooked my meals went shopping had an active

social life , my life is now an existence of misery and I have considered contacting dignitas as I now have no quality of life whatsoever I would be dead if not for private treatment I was at one point 6 stone and loosing weight continually very rapidly . I can no longer drive , I am housebound in constant pain I have seizures and severe weakness just typing this is extremely hard . I have had low grade fever throughout which they have ignored . I have to rely on a carer and my elderly mother of 82 I can no longer shop , cook, clean , pay bills , make phone calls / interact / socialise . I cannot do anything but sit or lie here my life is ruined I was young my parents had given me everything in the hopes I would have a good life I have be robbed of that . I trusted the drs when I first became ill I kept going as I deteriorated they had no answers apart from m.e / CFS I accepted it but I continued to get worse and loses more and more function if only I had done my own research then and not so far down the line. My father became ill and my mother and I could not leave him as we watched me deteriorate I knew that it may be too late for me that my only hope was to go abroad sadly my father passed away last year and then my mother was diagnosed with breast cancer . After ten long years we finally made it to the USA this summer for 8 weeks . My heart arthymia completely stopped my seizures lessened my fever became normal I had a picc line implanted in my arm I was bake to drive a car around a car park I will never know what could have been if I had been able to stay and continue treatment as we could not afford any longer we hoped the nhs would be supportive but yet again they were not , they would not do the dressing change on my picc line . I stayed out if hospital for the longest time in the past few years until recently when sadly my seizures or " funny turns " as they have been called by consultants returned as did my fever . My go would not work with my American dr and has now struck me off their list so prone toy I do not have a gp . I am shocked and saddened over and over my dad in his last years would burst into tears saying why won't they help you can't anybody help you he had worked every day of his life until he was 79 it literally broke his heart it has destroyed my parents lives too

I have lost everything...career, friends, financial independence, relationship...and now cannot afford my mortgage so am selling my home so my 84 year old mother needs to find somewhere else to live. I am unable to support my two daughters who are still in education. Apart from the day to day hell of living with Lyme, the stress of the impact it has had on every aspect of my life and those in my family is overwhelming.

Significant impact. Physical pain has begun to affect every aspect of my life particularly in the last 10 years

I have not been able to do everyday normal functions for over 8 months and have been out of work for same time losing about £6000 in wages.

I can't work because I'm so ill I'm housebound and my partner has had to give up his fulltime job to care for me 24/7 he baths me, washes my hair, cooks cleans because I'm too exhausted and in pain. We have a 10 year old son and I'm not well enough to look after him on my own so my partner does it all. It's so much stress on us all and my son is so young to see his mum so ill. The nhs won't help me so we have had to pay for armin labs and that was very costly indeed. I need the Co infections testing now bit money is such an issue I have set up a gofundme page for help. It's my last resort and I hated doing this it's like we're begging for money but we need help so much. If I go out to see my gp I use crutches and a wheelchair I spend everyday in my home all day long because I'm so ill fighting everyday till get to the next day. My headaches are so severe and the pressure is horrendous and my gp after over a year of me telling them how bad I am and I can't take it no more they have only just sent me to a neurologist. No scans ever have I had. I feel so let down by the medical profession and it's so disheartening all I want is help and to be well again. My son needs his mum again. I'm only 32 and yet my body feels like it's 90 years old. I get so low most days because I can't see a way out, I see my partner and son seeing me getting worse and it's not fair. Lymes disease needs so much awareness and funding and the nhs need to wise up before its too late. I

feel they have neglected me for so long and I'm sure it's the same for so many other out there and it needs changing ASAP thank you for your time

Lyme disease has left me tired and debilitated with no energy to socialise one I have finished work for the day

It is hard to find the words to describe the extent of the impact this has had on every aspect of my life. I went from being a fit and healthy teenager to needing help to get to the bathroom. 11 years later I am still fighting to get my life back. I dread to think how I would have coped if I hadn't been lucky enough to have the emotional and financial support given to me by my family. I have made improvements from the Lyme treatment I am receiving privately abroad but still have a fair way to go. It's hard not to think about how different things could have been if I hadn't been misdiagnosed... It took me 8 years to realise I needed to get properly tested for Lyme... Wasted years of unnecessary agony and suffering.

I used to have a life, now at 28 years old I have no quality of life. Because of symptoms, I can no longer work, go to busy places, lay flat or even stand up for any length of time. If my current private doctor cannot help me improve my health, my only other option is suicide to get me out of this living hell.

Having been ill since the age of 13. If not before. I don't have a life. Constantly in pain and tired etc heart issues too

I cannot sleep, I have brain fog, I have achey joints..... I am working full time but concentration has got less, I am moody and irritable. I am on antidepressants..... I just want to sleep all the time. However I am lucky that I do work full time..... At the moment

My life is over. I was a sociable, active, healthy, successful person and I am now totally unrecognisable. I am now housebound, have no job, no money, no social life, my long term relationship failed due to this illness. I used to hope to get better, now I just hope I die soon.

disagree with wording 'catching' lyme disease

Financial I have lost my high paying job after being unable to work for 1.5 years, resulting in a very significant loss of income. Because I own my own home (well, the bank does) i was deemed not to be eligible for benefits. This was very distressing at the time. I also struggled as I could get ESA support initially but then was not 'allowed' to do work from home this was really wrong and a disentive to get better.

Career This will have a significant impact on my career. I have a high degree, and had a post that was very high responsibility requiring years of training to do. My job was kept open for such a long time, but treatment delays and confusion over initial diagnosis, and the struggle to get treatment despite positive testing and EM rash meant that my recovery took three times as long as it should have. It is impossible to get another position like I had, and as I ended my work suddenly, I have lost so much.

Family life my partner actually tested borderline for lyme antibodies and was given the standard 'treatment' and really very much dismissed. We both are not able to work, and have had to have a significant change of life as a result of lyme, including considering the need to relocate to be closer to family.

social life My social life has reduced significantly, as for two years i really was not able to do much at all. Now there is so much stigma about lyme in the media that I do not actually tell anyone what has happened to me. I personally dislike the portrayal of lyme being associated with EVERYTHING alzheimers, autism, ALS, MS to me this is making really exaggerated claims and turns people off. It is now seen as a 'trendy' disease.

Because of all the media 'hype' I believe people I know have been misinformed and they frequently send me links to all sorts of bizarre stories about lyme.

After Doxycycline 200mg daily for 6 weeks (4 weeks from NHS, 2 further weeks of Doxycycline brought on the internet as pleading with GP was unsuccessful.) My 15 year old daughter became symptomless and remains so at this time 4 months later. Our GP absolutely refused to consider more than 4 weeks of antibiotics, he just stuck rigidly to the NHS guidelines, even though we thought she had had lymes disease for about 3 months by which time she had developed severe headaches and a facial palsy. The GP did concede that there was no consensus on treatment for lymes disease. As a family we felt very scared by the general lack of knowledge about lymes disease within the local medical establishment, even though we live on the edge of moorland and the total resistance to any review of her standard NHS treatment, which our research lead us to understand to be woefully inadequate. Advice from Lymes Disease Action UK was such a help.

I had to give up the work I loved teaching children who were out of school. My stamina and energy decreased at an alarming level such that I had to severely pace my activities. I had to give up my exercise class and stop swimming. I could no longer walk my dogs. I could no longer care for my mother in law and aunt, which meant they then had to rely on social services in addition to paying for additional help themselves. I lost many friends and became isolated. My life now is dependant upon my husband, who at 70 and living for the last 10 years with the stress of my illness (which has been exacerbated by the NHS when I have needed care and they have not understood and so not catered adequately for my needs, thus leaving me in an even more fragile state than before) which has taken its toll on him and he now has health problems of his own.

We must have spent about £30,000 on treatment and diagnoses, none of which has helped.

We cannot plan to do anything as I never know how I will be. We do not go out to social events. We have had to give up our dogs. We cannot visit our daughter in New Zealand.

Our lives have shrunk.

From very fit I turned virtually disabled. My cardiovascular symptoms are so severe that on a bad day I am unable to walk. I have to drive everywhere as I can't cycle. I work very little as my eyesight is so bad because my pupils can't accommodate. I have problems voiding my bladder and have to catheterise myself. I also have peripheral neuropathy in both feet. I have spent a considerable amount of money just getting a diagnosis abroad. I was discharged by the cardiologist after a year without diagnosis. I have to finance treatment abroad. NHS treatment was not effective.

It took me from active and athletic to tired and unable to socially interact and enjoy activities

Majorly. I have lost 2 years of living life. Excruciating pain endless debilitating symptoms. Neuro issues, memory speech problems weakness nausea pain joint pain all over body stomach issues hormone issues sight problems. Could only just walk up the road. I was a young healthy (never been to hospital rare doctors visits rarely eventook paracetamol kind of person!) ate well rarely drank kept fit and did yoga swimming cycling. Young family working as a teacher and all sorts of hobbies. Now im surviving. No money because its all gone on health care and trying to keep above water using what little strength I have to look after my 2 children. Fighting the NHS for any kind of diagnosis they are saying it is not Lyme but wont diagnose me with anything else. Patronised and treated worse than an animal suggesting im making it up and that I need to destress. Its torcher to say the least. I only manage to work 5 hours a week because I work for family and the hours are flexible. I would love to work more but im too fatigued and in pain to do so. Thankfully I am improving through antibiotics and herbals via a private Lyme Doctor and through strict diet and hundreds of supplements to help my body absorb the vitamins and minerals I need.

Bitten during an endurance hike on North Yorkshire Moors June 2010.

No erythema migrans, but 3 weeks later started to develop symptoms (stomach flu, followed by flu a few times, severe fatigue, insomnia, headaches, tinnitus, brainfog).

Diagnosed with Stress, Depression and CFS/ME in May 2011 and given several antidepressants

Stopped working Jan 2012 when brainfog became debilitating

Received official diagnosis in Mar 2014 in South Africa multiple intracellular bacterial infections, brought on by untreated Lyme Disease.

Treatment from Mar 2014 until Jan 2016 (4 week cycles)

Returned to work 4 days a week in Feb 2016

My blog: A run, a walk and a tick bite later (jeanettekruger.com)

It's ruined my life.

Had to give up work for good within a few months later more than 7 years ago.

Although I won ESA appeals they cancelled benefits to only for a year to those who qualified from working and paying taxes. All my family's savings have gone as we cannot survive on what my partner earns alone.

I've worked since my late teens and at 24 after putting myself through collage and uni I worked a full time job as well as evenings and weekends just to cover my bills but you know what I was happy. Happy and proud that everything I had was down to me and my hard work. Then at 26 I got sick and although I ate well, exercised three to four times a week, never smoked or did drugs and rarely drank I got told I had a "poor immune system" and sent away by the doctor! I was ill continuously for months and months before my fist banging and demanding for help made a difference. I got full bloods done and eventually told I have CFS/ME (in 2009). I did eventually see a 'specialist' who 'taught' me how to live with the condition (which was a complete waste of my time and the NHS money). Since then I've been constantly ill and you

guessed it I lost my job in 2012. when I got made redundant I managed to win some money £10,000 and do you know what I did? I tried to set up self employed because I WANTED to work and I thought if I could be my own boss i could keep my independence, live life and go back to working like I always had but work hours to suit me so I could manage my health. But it didn't work like that because I got sick and the £10,000 I had was gone I had invested the lot trying to work and not be a burden on benefits. I tried a number of times to find work but i struggled to find something I could travel to by public transport without making myself fatigued from travel and something that could pay me enough. I eventually got another job but it was part time but I struggled with paying my bills and eventually got so sick I was let go. It was only in 2012 the year I met my now husband that he told me to stop pushing myself as it just made me sick. So I rested but I was refused benefits as my partner (st the time we weren't married) wasn't enough. It was never suggested that I should have been claiming sick benefits. When I had claimed the job centre were happy to tell me to work even though I would be looking and feeling like hell, constantly having to take in sick notes because I was too ill to get to my appointment. It was a joke. In the end my husbands friend knew a private specialist doctor who agreed to see me and it's been through her treatment that I discovered I have Lyme and that's likely what I've had all along! I do now receive sick benefits as the years of damage to my body has made me worse than I have ever been and I rarely leave the house. I can't walk far as I'm so fatigued. I don't leave my house without my husband as I need him to drive even to take me just down the road to my doctors when I need to. I have crushing headaches, my body aches, I get confused periods where I can't say what I want or can't find the word and I get tongue tied, I forget things, I feel like I'm crazy drunk (I'm T total), I have allergic reactions to known foods, I constantly feel like I have infected sinuses, I'm so unbelievably tired and lethargic and that's when I've just started my day. My energy is none existent, I have to fight to get through my day. A journey to see my family or friends can completely knock me for days, I have multiple food sensitivities, I am deficient in many things, I have thyroid, Adrenal and poor mitochondria function. I

have a bacterial overgrowth in my body, I have stomach issues, I have night tremors and night sweats and sleep problems so can't even share a bed with my husband! I'm 33 for Christ sake and I have no life. I want to work and I want to be well, but the NHS just don't help. They always say their hands are tied. Their blood tests are limited and their Lyme test is so worthless I don't know why they bother! There is enough research out there to show that Lyme can seriously damage the body I don't know why the NHS are sticking their head in the sand. The way I see it is if they pulled thir finger out and had reliable testing so people got detected early and the necessary treatments they would have a lot more people getting well and being able to go back to work. Instead people get told they have all sort of illnesses that the NHS do nothing for and the people get left to fend for themselves while claiming peanuts from the government! And I have to point out when you pay for your own care, treatment and debtor it's not cheap! But the thing that private medical care shows you is that the NHS need dorm thing doing because it no longer is doing the job it was set up to do. Too many people taking from the post and not enough people paying in. I would rather pay and get the care I need than not pay and get care that isn't even doing anything to help me!

I have been unable to hold down a steady job for almost two years now, I've been suicide on a number of occasions. I'm in constant pain and the fatigue means I can't think straight enough to do daily tasks properly. Relationships with friends & family have been strained by the lack of support I have had. I'm only 26 and It's ruining my life.

Unexplained cramp and stomach pains

Very tired all the time.

Work / family life suffers as I have to catch up with work at the weekends & evenings. Financially suffer, as I could have worked longer hours with a better paid job; but instead I work from home for a small charity run preschool, which doesn't pay great.

I am housebound and have become socially isolated. It is very hard to maintain friendships when you don't have the energy and balance to go out and about and do activities. I have been single for over 3 years as I am unable to go out to meet new people. Due to the chemical sensitivity, I struggle with inviting people over as most other people use strongly scented products (something I really wish the government would regulate more stringently, especially in light of the growing number of studies that scented products are damaging to our health). Due to my neurological symptoms I find using the computer very draining and get sensory overload, so making and maintaining friendships on the internet is also troublesome.

I am at the point where I can't wash myself every day, despite a desire to, and have to use a bath lift for fatigue and the dizziness to keep myself steady when I do bathe. I basically don't have what most people would call a life.

It has ruined my life. I am 24 years old and been bed bound nearly 2 years now. I should be out working and living my life but I'm not.

My joints seem to ache more even though I thought the 2 weeks antibiotics was meant to cure early Lyme

In the first 12+ weeks after I became very unwell, it was devastating. I had to rest constantly and was in severe pain. I couldn't make plans. I had to leave my part time job as I was signed off sick for so long. I have had to spend money on private testing and supplements.

What life? I was a young vibrant business owner, I ran several businesses, modelled professionally, travelled the world and my passion was the great outdoors. I was a well trained competitive athlete in peak shape during what should have been the best years of my life and I lost everything due to Lyme. Condemned to not so much as seeing the

sky for years from my bed, crawling to my bathroom, struggling to feed or wash myself and crying myself to sleep from the constant pain and suffering. 7 years of my life gone and my prime childbearing years almost lost. Incomprehensible suffering and anguish. Now 5 months after diagnosis and with the little treatment I've had i'm making improvements and beginning to see the light for the first time, although now dealing with epilepsy from the Lyme. I'm fund raising to get to the USA next month to get the correct help, support and treatment I desperately need to help me recover my life once more, hopefully get married, have a family and regain my career after what can only be described as a hellish battle with the U.K. Health system.

I had a full time job, was a viable tax paying member of society with had an active life (sports) and a good social life. I lost my job & my ability to support myself, lost my self esteem. As a doctor's daughter I was brought up with faith in the NHS who abandoned me. I was left housebound, frightened, depressed and isolated and forced into debt and relying on family support to keep a roof over my head and to seek private treatment for my Lymes disease.

I an now virtually bedbound. I lost my job in banking with loss of earnings. I have experienced loss of social life (Yoga and Aquafit groups, church community, choir, charity works, friends, etc). I presently have enough energy for about 1 hour, and then crash for the rest of the day. I am normally a very positive and upbeat person, but I now feel very depressed (a) by the state of my health and (b) by the callous, uncaring attitude of many doctors in the NHS who know that I have neuroborreliosis and either ignore or deny it.

Lyme disease has taken away my mobility and drastically reduced my quality of life. I am now a shell of my former self and the disease affects every aspect of my life and family. I struggle to be the wife and mother I was intended to be and wish for the day when pain won't accompany every waking moment.

unable to work, unable to carry out physical jobs around the house. I can not interact with my child in the manner I would like. I have to consider how far I can walk before committing to going anywhere.

My whole family has been affected by this illness. My son also has Lyme. It's a contact battle everyday trying to find health. No where to turn to within the NHS. This is frustrating, friends and family constantly asking if we have been to see the doctor? They don't understand the doctors can't help. My husband is the main breadwinner and the pressure is enormous. Our daughter is often sad and worried about her brother who is bedbound. We try not to talk to much about our situations as friends and family can't cope hearing how we are. Most of our money goes on private treatment.

This illness has caused significant financial hardship, affected my ability to socialise and have any worthwhile relationships. It has caused significant isolation and loneliness.

I cannot work too long hours now in a cleaning job or dancing as it affects my back and will leave me bed bound for a short period after

Overnight I became unable to work or socialise. Energy levels dropped to 5%. My memory was so bad it seemed I was going senile. I had many other neural malfunctions. It was extremely embarrassing.

I borrowed several thousand pounds to pay for private treatment. Had to to claim sickness benefit & DLA; it was a dramatic drop in income and I had to sell my large detached seaside house, downsize to a a deprived area with dreadful neighbours & very poor tradesmen to repay the loan. I lost my long established network.

For about 15 years my 3 adult children could not accept I was ill, they were used to a strong capable mother. It was deeply upsetting and alienating.

With only enough energy for survival; stuck home alone 99.9% of my waking hours meant I could not make new friends. I have been extremely lonely.

Everything....my teaching career, first marriage, sanity through neuroborreliosis, house nearly, social isolation when house bound for years. I worked hard to gain a First and loved my teaching job...I put a lot in to public service and feel let down after 15 years of being sent to a psychologist because they couldn't find any explanation for my symptoms...you feel humiliation and anger plus despair when time and time again no one believes you. We are spending £500+ a month on private treatment from Dr Sara Myhill and others just to keep my head above the water....something needs to change, especially when this disease is so close to syphilis and others. Testing needs to be thorough.

Already suffered from increasing osteoarthritis, so to now have increasing and additional joint pains is a significant impact on my life and that of my husband who already takes on so much to assist me in our day to day life. Not to mention the impact of intermittent depression on us both.

Totally

I cannot work. I am largely house bound. I have been bed bound for two years. I live with my parents who look after me. My GP supportive, but knows if I see other consultants it will be a waste of time. He is happy to follow the advice of a US Lyme infectious disease doctor instead.

Over the last few years i have been very sick through lyme disease and coinfections. I havw been in so much pain, both physical and psychological that i have thought about ending my own life on several occasions.

My life was excellent before I got sick. I was a happy healthy, marathon running, nutrition conscious guy. Amazing family, great job, played guitar in a blues band etc. It has literally tire me apart

You can not call it life. Zombie is a better way to put it. I'm disappointed about the ignorance you get from NHS here. I work for paying my treatments and I lost hope that doctors here will ever help.

I don't feel as though I'm living, only existing. I have symptoms everyday and can not predict how I will be feeling the following day, it's affected my social life to the point where I avoid arranging to see friends, as I end up having to cancel most of the time. I'm either too fatigued, or in pain.

I worked in the financial sector. I was made redundant from my job and I'm unable to take on employment due to many of my worsening symptoms, but especially the muscle pain, brain fog, not being able to focus and short term memory issues.

I currently live off savings, which pay for all my medication. I'm not sure what will happen once money runs out. I'm not claiming any benefits. There is also strain on my family as I've had to move back with parents, they're great, very understanding. However I often feel anxious, short tempered and low, I've had to give up/put on hold all my dreams and ambitions. With so many advancements in medicine, this is not how a 40 year old woman should be living.

Spent thousands on Lyme treatment. Got accurate diagnosis of Lyme disease after 8 years of deteriorating health and misdiagnosis of ME. 10 years ago had to retire on ill health from NHS. The very long term strain both emotionally and financially has had a devastating effect on our marriage. It's now completely broken down. We have 2 boys young teenage boys who are also heartbroken because of this. I am 90% bedridden and have missed many special events for my children because so weak etc eg Birthdays outside family home etc . I am unable too take my children out and do all

the normal activities which mums do with their children. I have no social life. I pay for a private carer too help with food preparation etc etc. I have no extended family too help me. I feel completely isolated from the community.

With treatment I know I can get a quality of life where I can take my children out for a meal or watch them play football on Saturday. Without treatment I know I will continue too deteriorate and eventually die of Lyme disease. The NHS have offered me surgery for a stoma because my bowel function is so seriously not working. All of this could have been avoided had I been given an accurate diagnosis and treatment 10 years ago when I became too sick too work for NHS.

My life went completely off course when I caught Lyme disease at the age of 25. It isn't an overstatement to say my life has been ruined completely as a result.

I lost my promising career, and indeed any chance to work at all in any kind of job. I lost my social life and virtually all of my friends over the years because I am too unwell to participate in any kind of "normal" life. I have been unable to have a relationship as a result of being ill and therefore have been unable to have a child or children of my own. I have been a burden on my parents who have had to look after their adult child for the last 23 years. I lost all my independence. Because I am still ill, I am now unable to help my elderly parents as I would like to.

Perhaps now of this would have had to happen, if I had been treated appropriately by the NHS in the early stages of my illness. If that is the case, then it is nothing short of tragic and a disgrace in my opinion, that a young adult should have their life ruined by the inadequacy of our National Health Service.

Withdrawn from social life. Part time work is all I do. Come back from work and spend all the time I have to recover. Useless at home, hardly do any cooking or cleaning.

Withdrawn completely from all social, family, church, sporting and community activities. No holidays, no travel, wife has to run household. Had to employ help for garden and household maintenance work which I would normally do myself.

My whole life has been affected significantly. At the age of 22, I was beginning my life and career, when one tick bite (misdiagnosed as ringworm) turned everything upside down.

I petty much demanded a blood test after 8 months of suffering with a growing number and severity of symptoms. The GP still didn't know about lyme disease and was adamant she knew best. Strong positive with heavy and debilitating symptoms including headaches, joint pain, fevers, cognitive ability loss and many others.

It has stripped me of studying to become a nurse (my career and education), I have lost friends and partners, I have lived in poverty many times, lost jobs, lost my spark through pain and sadness at the situation and felt the highest level of frustration anyone can feel.

After getting the 'NICE advised' length of antibiotics I was left to fend for myself whilst my symptoms continued to present (My GP said they would get better in time). They have gotten far worse. The last year I haven't been able to work at all. You cannot move on with your life, enjoy life how you should and you continually watch friends and family overtake you in the road of life. It is a very mean and complicated disease but one that we need to know more about, we have probably only scratched the surface (pardon the pun).

I have now been diagnosed with ME and have severe pain in my hips (which have steadily got worse over the years). My bloods are 'normal', of course, because the antibodies (if at all present) reduce dramatically in numbers after time with the bacteria. Our bodies struggle to recognise them and the 'behaviour' (for lack of a better word brain fog!) is incredible, possibly changing their 'coats' and 'hiding' from our immune system. Whilst wrecking havoc everywhere else.

It is a serious illness and people in my situation are constantly scrutinised, questioned and made to feel guilty. This needs to stop.

I want to have a career, be able to walk my dog when I want, or put on my socks in the morning! I played football, tennis and loved hillwalking I will probably never get those hobbies back but I don't want to be written off at the age of 28! I have struggled with depression due to not being able to exercise and the pressures that the disease brought. I now practise meditation and mindfulness just to stay afloat.

I don't have the education (or luxury) due to the disease to follow my dreams career wise but will settle for anything now out of frustration. I want to have a family and be able to support one. I want to be pain and symptom free, even just a bit to let me function. There may be some of this I forget to write but I hope it tells you the right thing. That Lyme disease is a monster that rips your body and life to shreds!

No one should ever have to go through this. It is in our power to stop it. Please let us do something now. It makes me so angry and upset that people at the age of 22 or younger are still susceptible to the loss of everything like me. It shouldn't be allowed to happen!

Many thanks,

RW

I'm a carer for my daughter and my mum. We all have Lyme disease. I think it was maternally transmitted. I'm now struggling to take care of myself and my daughter and my mum has now had to go and live with my sister as I can no longer take care of her. Lyme disease has devastated our lives. It has cost us £100k. We had to go to the US to get treatment for my daughter. My husband has to work very hard to support us financially and now that I'm ill too he has to take care of me when I can't manage. We do not use the NHS as we are fed up with their ignorance and lack of compassion. We order drugs from the US and it costs a fortune. Each week we have acupuncture and lymph drainage which help with symptom and pain. None of this is provided by the

NHS. I am ill now due to the stress of caring from my daughter. Our lives have changed totally. And the worse thing is we have no idea what the future holds.

Depression

Passed from pillar to post

Not taken seriously

Consultants blaming other diseases rather than Lyme and coinfections

Have a degree and feels like it has been all a waste of time as now working part time due to brain fog and pain

I was an overachieving accounting student self funded trying to raise my family's standard of living as a single parent. Now I cannot retain information and have had to put my studies and my life on hold. I cannot take the children out much and when I do, they are supporting me quite literally in case I fall over. I'm still having neurological symptoms and skin symptoms and not been tested for any coinfections

- Psychometric testing at Kings Centre of excellence showed impaired functional memory for age and intelligence.
- My job in the NHS is constantly under threat because I can't perform WTE hours and struggle cognitively; making mistakes.
- A formal diagnosis of chronic fatigue syndrome is unhelpful. The offer of CBT is undesirable.
- I have to rearrange my work days to accommodate hospital appointments.
- I frequently have to lie down.
- Most personal relationships have broken down.
- I can't perform day to day tasks as people of a similar age.
- When doctors are sceptical about the cause of visually obvious symptoms, in the face of variable test results, it's demeaning to keep humiliating oneself. The doctors who support the patient say their 'hands are tied'.

I've lost my job I loved, my home I loved, my career I loved, my family I loved, many friends I loved. I've lost all the financial proceeds from my lifetime in work and am left penniless. I have at times lost my self respect and any semblance of self worth, as I've been treated so badly. I've lost my mojo, the ability to socialise at all, the ability to read or write, the ability to play or even listen to music, the ability to do anything but lie there in almost endless agony, being called a hypochondriac by the NHS, shouted at, laughed at and generally treated like a subhuman.

My husband and I are 24 and when I started getting sick I couldn't contribute to our marriage or household the way I wanted to. He had to take over all of the chores just so I could make it through work and come home to sleep and recover for the next day. It put a strain on our marriage. We spent 15,000 out of pocket in 2015...treatments were not covered, they only partially covered doctor appointments. I had an early miscarriage that was most likely caused by Lyme. My husband is getting tested for it now due to symptoms. Even after treatment, I still have lingering nervedamage. I am thankful that treatment did help, that the appointments were partially covered, and that I was able to keep my job, but it is not easy. Lyme is a lifechanger.

NHS ophthalmologist suspected Lyme disease after being treated for chronic keratitis episcleritis conjunctivitis for 1 year the RED eyes would persist. He used NHS test for Lyme but returned Negative? Ophthalmologist still suspected Lyme and referred to NHS infectious disease dr who told me the NHS test is 100% accurate so I don't have Lyme even though ophthalmologist still and still does with followups for 5years with private treatment from USA. Spent at least £80,000 on diagnosis,ruling out all other conditions and ongoing treatments/travel etc.... No longer in contact with my friends, should do more things with my kids, own business badly affected. The worst for me is missing being a real father for my young family for a 3 & 5 year old for the past 6 years.

Nerve pain, insomnia, tinnitus, twitching, forgetfulness etc..... continue and the torment of death in the future!

I was a fit, active child. My ability to learn and remember things gradually decreased, which affected my university career significantly. I somehow managed to keep going, despite relapses every 34 weeks. I dreaded job interviews coinciding with these relapses, as I inevitably made stupid mistakes. I started to call people by the wrong names and, although I'd been able to spell very well since childhood, I began to make mistakes. It was all quite embarrassing and I didn't understand what was happening. Friends stopped getting in touch when I didn't have the energy to go out. When the migraine/vomiting cycles began I lost a lot of weight and people assumed I had an eating disorder. I couldn't seem to get the weight back on. Eventually I became so ill I was drifting in and out of consciousness. I was very isolated by then, and very frightened. My blood count crashed and I was given a blood transfusion in hospital, but no further investigations or treatment were given. I was so desperately unwell by then I felt I couldn't survive much longer. My life has been completely derailed in every way by these illnesses, and no one seemed to care. I used to have a flat in London, a good job, hobbies and friends. All of that has gone.

The severe symptoms have rendered me unable to work and support myself (I live alone). I have tried several times to retrain in less arduous work than my chosen career, in vain as I remain too ill even to work as selfemployed. I have striven unrelentingly to gain enough health to return to caring for myself adequately and being able to earn my own living again.

I have spent all my life savings supporting myself and paying for modest private treatment (I never had enough for expensive private treatment abroad), and now I have nothing for retirement (I should have retired at 60yrs old but will have to go on another 6yrs). I have been ill for so long that I have been unable to save for a pension.

Like many of us the only way I can keep from losing my home is to rent out to other people, but I will eventually lose my home when the interest only mortgage runs out. Physically Many days I am in pain, dizzy, out of breath, nauseous so that I am unable even to sit up in bed; many days unable to make food; many days unable to remember to eat; or how to prepare food. When I get a good day I try to cook and freeze food, but this exertion leaves me exhausted and in pain for days after to recover.

Many days unable to read. I have to prerecord TV programs with subtitles as I always fall asleep, I also have to halt the program frequently to make sense of the speech or action and rerun it.

The neurological/ cognitive symptoms leave me unable to problemsolve, write, think clearly, speak coherently. I struggle to make sense of paying bills and am always making mistakes. I look normal but am trapped inside a body that will not function or think normally.

I can no longer socialise, go dancing, go to the pub. It is too exhausting for me, I have no strength or spark. I can't make sense of people's speech. Hyperacusis makes it painful to be in noisy places, in crowds.

Example: I tried going on a citybreak for a few days as I was determined to celebrate my birthday doing something I loved. I had money stolen from me at the airport as I was an obvious, vulnerable target. At my hotel I spent the daylight hours in my room in agony with excruciatingly painful limbs in drenching sweats. I managed to walk out onto the nearby streets for an hour in the evenings, returning to my room for a sleepless night of more drenching sweats and pain. I used to love travel and backpacked on my own all around India, Thailand, Africa and further. Everything I love has been taken from me by the neglect of being treated improperly for this disease. Being this ill for this long has isolated me from my family who will now have nothing to do with me and from most of my friends the only ones that remain are those who have health problems themselves and understand what it is like to have long term debilitating illness. I used to sing in a choir I am no longer able to sing. I had a full and active life and used to go skiing, horse riding, dancing, bird watching, long

distance walking, swimming and working out in the gym. I can do none of these things and have even had to give up sitting in the sauna.

I had a full and active career in my dream job as a research scientist which I have most reluctantly had to give up many years ago dreaming that I could one day return. I miss the mental stimulation of my job, being with other work colleagues, the satisfaction of completing work tasks, the kudos of being good at my job and the pleasure of earning enough money to run a car, pay for my home, raise my children and take occasional holidays.

I am left with fear and despair at the certainty of failing health, increasing poverty and a miserable hand-to-mouth existence in these last years of my life. I feel robbed not only of the best years of my life, as this started in my early 30s but also of my twilight years that should have been a time of reflection, safety and quiet contentment.

After year I have just given up my job.

Social life gone.

Unable to look after grandchildren like I use to.

Lost earnings. Been on half pay for last 6 months.

Been unable to go on holidays abroad (use to go away 4 or 5 times a year.

Unable to drive far.

Inability to exercise.

Ruined life

sporadic neurological problems, gross fatigue, poor sleep patterns, severe at times joint pains and muscular aches, severe bouts of coughing due to mucus in throat trapping small food items often leading to hypoxia blackouts causing damage to face and eyes and loss of spectacles, severe tinnitus, very poor short term memory, impotence, optical migraine, severe pains in and at back of eyes,

I have no quality of life. My life consists of exhausting trips to the bathroom and recovery time in between them.

Yes, I tried to go back to work as a nurse in theatres at night, I managed a year but had no quality of life as I was constantly exhausted. I gave up in Jan 2013 and continue to work part time doing the books for our own business. I have since been diagnosed with RA probably as a result of being ill with neuro Lyme. My quality of life is much better now, I still have bad weeks but generally I can function normally but have never quite regained my previous energy levels.

From a active woodworker who never took time off, who can't work for more than an hour.

Every spare time was fishing on the beach, now I've not had the energy or inclination to go fishing in 3 years.

My wife worries about my mental state constantly and she works so hard to keep us. I'm the man who should be supporting her

I have little QOL. I never achieved my potential in life, both career wise and financially. I have no family life and little social life. It is a different universe to life as normal people know it.

This illness is going down the generations and the country is building up a huge backlog of problems.

I could have been earning a good salary, instead of costing the country money and being a drain on the nhs and the benefits system. It appears the medical profession is not treating anyone properly, so half hearted attempts just cost money by repeating the same mistakes and never sorting the problem. Doctors have too many psychological problems and are behind the times. There is a fundamental problem with their training and understanding of illness.

yes,

i am in pain,

from joints, i suffer real bad with brin og, and so on, i get dizziness bad, i have tinnitus, i am very agrophobic, thank goodness i have to go to work or i would ever leave my hme, i am happy in my safe places, my bedroom my work place my mums house, i find it hard to cope, i do not know how long i can take it, the palpitations are bad, im now waiting for a spinal xray to see if i have arthritis in there, my eye sight is terrible and getting worse, so many things,

20 years ago my life changed with a devastating illness diagnosed as a summer virus. I had previously been bitten by a tick then several days later developed a perfect bullseye rash then that was followed by the summer flu.

I knew nothing about Lyme.

At the time the 3 events did not seem to be related.

With hindsight I realise they were.

I never fully recovered from the summer flu.

I went from a normal, fit and active female to an old woman.

I had no idea what was wrong but set out on a long slow road towards recovery which never came. I made every effort to be well again. Now I realise I was on a path of remission and relapse.

My GP practice at the time had known me well and conscientiously tested me for evidence of each new symptom beginning with arthritic/ rheumatic symptoms. Heart problems, chest, IBS, anxiety and fatigue were all tested for and I used to joke that I was the most organically sound person I knew but I was also the sickest.

10 years later I read about Lyme and recognized my story. I went to the GP and a blood test was done. The result was negative so once more an illness without a cause.

10 years later I revisited Lyme when I realised that tick bite with EM rash means Lyme with or without positive NHS serology.

Unfortunately the NHS consultant and therefore GP don't .

I was retired early with a CFS diagnosis.

Lyme and lack of treatment for it compromised my life completely. My personal, private and professional life were never to be the same again. I was never the same again.

So long ago that there are few people now who knew me well.

It has cost me a lot.

Even if I found my own path to partial remission the relapses were devastating and the slow journey to recovery had to begin again.

It cost me a lot in terms of everything not just financial.

At 40 years old I became 60. At 65 I'm doing ok for an 85 year old.

My quality of life as a result of Lyme and more importantly because of the NHS response since moving to Highland Scotland has been compromised and diminished.

At 21 I was full of potential. I graduated from one of the top music colleges in the world and started my own music production company. Several months later, every aspect of my life was wrenched apart by the express train that is Lyme disease.

Instead of successfully developing a career I was forced to stop by severe symptoms which left me feeling flu like and rarely able to leave the house. Nearly all my money has been spent on private doctors and treatments leaving almost none spare for life. I am paying for doctors and treatments with disability allowance that is normally used for disabled people to live on.

As I am rarely able to leave the house, social life is extremely limited. I have made the best of the situation by having my few friends visit me at home.

Spending most of my twenties on disability living with my parents has not been ideal.

Despite that I take a positive attitude, I know it affects my parents enormously and causes great sadness to see me so ill. My mother has said "it's been the worst thing that has ever happened to us".

I have worked relentlessly, spending literally thousands of hours to finally find out I have Lyme disease. I have seen over twenty doctors. I have spent all my resources and I am living with a very poor quality of life.

I have been so exhausted a lot of things I should have done have gone undone. My marriage has suffered and I have had to close my business of 15 years.

At the age of 46 I was a super fit long distance fell runner. I became ill in the summer of 2012 and was admitted to hospital with suspected Guinne Barrie syndrome. After spending the night in hospital I was discharged with a diagnosis of PVF. Readmitted by my GP 3 days later and told you're white blood count is a little raised and it's PVF. Had brain MRI scan 2 months later all clear. Then left to my own devices. In bed for 3 months. Visited GP for more tests and was refused Addisons and Lyme tests. Prescribed Mirtazapine to help sleep issues. 1 year later I started Perin Technique treatment. Some routine bloods then picked up that my liver enzyme ALT was raised (I now know this was Ehrlichia). 3 months later it was 210. Has liver scan and told okay. Went private and told it might be Mirtazapine but unlikely as only on 7.5mg. Said it's probably fatty liver disease which I said not s chance. Picked up low cortisol and referred me to endocrinologist as thought I had Addison or prolactinoma. Both negative but low testosterone picked up. Had short testosterone treatment that made me very ill.

My recovery was about 50% when I became very ill again in June 2015. Loads of tests and visits to hospital since, including negative Lyme test. GP is a new one and can see I never visited s GP since age 17. She accepts the Armin Lab results and will prescribe antibiotics for as long as I want. Also buying rife machine and Cowden protocol. Have also bought a fir sauna.

2 weeks on antibiotics.

Lyme has destroyed the life I always thought I'd enjoy. I am almost dead inside. But there is a part of me that will live on. Lyme will not kill me.

Completely. I am a different person now.

Was hoping to do research, career but all changed. My outlook on life and peoples attitudes has changed. Learnt who your friends are.

Forced to do my PhD part time.

Can't do what I want when I want.

Other people don't get it.

Isolated.

I retired earlier than I would otherwise have done, which naturally affected my pension entitlement and lost me some years of potentially high earnings. What energy I have is mostly spent on running our household because I have other family members with Lyme, who suffer more from it than I do. My social life is therefore limited and general living is unrelentingly stressful. The effects of long term chronic infection inevitably wears sufferers down and can make them hard to live with at times. The stress is not helped by most of the medical profession and the general public, and even some supposed friends, thinking that the problem, or at least some of it, is in the mind.

I am devastated. I have a lovely and understanding GP but who is forced to defer to a team of specialists...who are arrogant and not interested in probing for answers. They are for the most part siloed...can't see wood for the trees and most "see" whatever their specialty is to the detriment of considering Lyme and coinfections. An eminent specialist saw me, didn't conduct a physical exam (he/she is a neuro) and didn't take a history...just sent me off for a bunch of tests, pronounced without said history or exam that he didn't think I had Lyme, and then sent a clinical note to all and sundry noting that he/she had seen me and that the patient "thinks she has Lyme" despite negative tests...when in fact I had several recent positive Lyme tests, both NHS, Porton Down,

and private abroad. This for me sums up the arrogance. A simple readthrough of my chart, the preconsultation briefing email I had sent, or listening to my pithy briefing at consultation would have cleared up this keyfact. I have managed to have 2 weeks co amoxiclav and 12 weeks doxy and am still sick. There is no suggestion of further steps and in fact St G ID sent me home as " well". Despite positive coinfection results from Armin and the failure of anyone to ttest for the two most commoncoinfections (babesia, bartonella), the NHS has yet to test for these8 months later. I am sick. In 2013/14, my tax return showed 7 figures of income, a lot of it paid back in tax. I have earned nothing since then and doubt I ever will earn even 6 figures again if I don't get well. Finally, this was all preventable. I presented to a GP with a rash and asked to be tested as I learned I had been in a Lyme area. Denied. Two weeks later, I ended up in A&E at St George's when the rash conti ued expanding. I spoke with the consultant and begged for the Lyme test. Denied. And with this, the early opportunity to rid the body of Lyme easily was gone. Six weeks later, neuro and joint symptoms and fatigue set in. it . I have. Deteriorated steadily since. Shame on the NHS, shame on St G, shame on the medical establishment and its arrogance and lack of curiosity and interest. Isn't this supposed to be the best and brightest? I don't think so.

I work as a paramedic so fatigue has been a real issue with long shifts and irregular shift patterns. If it wasn't for being able to access private treatment for this condition I would have lost my job.

I lost my business... my partner ...i got into debt ...my son went off the rails started stealing so he could buy himself the things I could No longer afford

social life is virtually non existant, although I still work I find it very hard to fully function

Gave up full time apprenticeship. Commenced another after 10months recovery time. Had to reduce working hours by half. No social life at all. Mentally and physically exhausted 24/7. Poor sleep patterns, food intolerances and family life and holidays on hold for past 5 years due to tiredness.

If I hadn't realised that my rash was lyme and suggested it I know i wouldn't have been diagnosed with it by the two gps i saw or the a&e doctor who said there was no lyme in Europe. I had to push for it to be considered and given any antibiotics. This ruined relationships with my family members who believed the doctors over me. As a result of having to see numerous drs there was also a delay in starting treatment. Earlier treatment might have eradicated the infection whereas now i have had no relief from symptoms for many months. My quality of life is greatly reduced currently more because of the emotional turmoil it has caused. I am afraid as there appears to be very limited knowledge and recognition of lyme within the nhs once your symptoms continue past 4 weeks. I have had to seek treatment myself and pay privately for help which has eaten into our savings and i am now hesitant to spend money on things that aren't essential for me and my family in case I need that money to seek more treatment in the future that I will have to pay for. My marriage has been strained to breaking point due to the pressure of having to seek and make decisions about treatment that I feel an nhs Dr should have been doing on my behalf. I have put my career on hold as my future health is uncertain and my stamina reduced so I doubt if I could manage more hours than i do currently at work. My free time rather than spending it with my children is often taken up with researching the condition and the possible treatments and supporting supplements.

Fortunately I am retired and on a pension, however I have lost days with having to spend time in bed with total exhaustion. Fortunately I have an understanding and caring husband. However I believe other close family relationships have suffered through my being on occasions very depressed. This applies to friendships as well.

These take time and effort which I have had in short supply in recent years. My mobility is impaired and I have fluctuating pains in various parts of my body most recently my hands and wrists. In 2014 it was my feet and I struggled to walk for several months.

I used to be very energetic, drove all over Europe as a lorry driver, spent time with my kids, holidays abroad, was in the Merchant Navy at 16, now I am fully housebound with no future at 47

I am only eleven, and have been unable to run around and play with my friends for almost two years. I've missed so much school, and wasn't able to go in at all for over a year; mum has had to give up her job to look after me. I go to school parttime now, but can't remember things like before, so am finding the lessons much harder.

I have struggled to work and have only managed parttime work since late 2006. As a business owner this has affected my business. I have been unable to put the effort in to get enough new work, resulting in the loss of one employee. I am now considering closing the business as I cannot cope.

For many years I was unable to maintain a social life resulting in the loss of all but a handful of friends. I still need to pace my activities now.

I have paid for private treatment since 2010 when I was refused further NHS treatment. So far this has cost just under £30,000.

I got the be rash after 3 weeks of the bite. I did a 6 weeks course of Abx. At the time of the bite my mental function was messed up. I could not stand light or sound. And was bed ridden for 3 months. Im slowly improving and gaining weight. I have trouble with my short term memory. Which is frustrating. I get pain down one side of my body. In my right hip. Knee and elbow. And right side of my hips. I get pretty much daily pins and needles. I suffer with random heart palpitations. I'm cold through out the day and

sweating at night. I'm shattered thro out the day a wide awake at night. The only 2 common demoniators in this is the bite and since then most of this seems to be connected with my mental cycle. The pain started when I bleed in the begining But is expand get to the point that when i had my last bout of pain, it was 12 days before I started bleeding. The intense pain lasts until the day after I finish bleeding. I've requested an hysterectomy. But I've been told I'm not eligible for one.

I am not able to work so I rely on the one benefit I receive. I live with my parents, and while this saves me financially, it makes me feel less independant, yet I know if I lived alone I would have to hire outside help.

Most days all I can is get out of bed. If I have an appointment on a bad day, I need help getting dressed etc.

I have lost a lot of 'friends' due to not being able to do the things I used to. But I'm choosing to look at that as a good thing.

I struggle sometimes holding a conversation which to people who don't know me that well, may come off as rude and like I'm not listening properly. I used to be a very laid back person, now I get frustrated/angry/upset when I forget things/words and when I get word block.

The symptoms have been insidious... for a long while I was beating myself up for being lazy when I started falling asleep on the sofa in the afternoons. I began to find cooking the dinner an enormous challenge, let alone my work as a coach, which requires me to be particularly alert and attentive. Over a couple of years, I found it increasingly difficult to follow a thread in conversations, let alone writing, and at Christmas, after 3 attempts at putting together a simple coaching blog, I decided I needed to stop my work and concentrate on getting myself well. I had also freelanced in media work, and one day was booked to do a number of TV interviews. On the day I had a raging migraine they last up to 5 days but the production team/equipment/venue/guest was booked and I just had to go ahead. A banging head did nothing to help my

already compromised ability to hold a thread together, and I have not done any freelance media work since. Before I had the Lyme diagnosis I kept trying to inspire myself to push through in my work, thinking that my motivation must be lacking, and went on several courses that really interested me. One of them, in 2013 was an NLP Trainers' course. Although I qualified, I was dismayed at my lack of retention no matter how many times I would revise certain things, my brain refused to register them. Then last year I began a coaching course in London that I felt passionate about. It is being taught in modules throughout the year. The first module was 3 days. I made myself see out the 3 days, but realised that the following 4day modules would be beyond me. Especially when a little later I went up to London to get my bloods drawn for the Armin tests, and came home completely exhausted. Sadly, I have since had to pull out of my exciting new course. In terms of social life, I have found that to keep free of debilitating flares I need to follow a very stringent diet most restaurants, and also dinner with friends, are out. Going out for a drink means an evening on sparkling water or mint tea. I do find that as long as I stay on this diet and take the enormous amount of supplements I have amassed to keep down my symptoms, I can go to the cinema, or spend an evening with friends (although following the plot/keeping up with conversations is another matter). However, there have still been times when I have been too fatigued (fatigue remains an issue I haven't yet found a supplement to knock this on the head) or have suddenly been hit with a random flare, and have had to cancel. So for instance, my husband and I were looking forward to spending New Year's Day with friends, but when the time came I was in too much pain and too fatigued to go with him. I also used to go out jogging, but one of my initial symptoms was ankles that suddenly turned weak. One day I just had to stop jogging, and back home I discovered that both ankles were extremely swollen, although I hadn't injured them. I had to wear ankle supports for a fortnight, and walked with a limp. Since then I have had to stop any jogging exercises at the gym and concentrate on weights something that is counterintuitive with fatigue, but necessary to move the lymph round the system. Besides having to stop work, having Lyme has cost me a

fortune in other ways. I spent £1200 on getting Lyme and the coinfections diagnosed, a few thousand on consultations with nutritionists and functional medicine doctors to try to bottomout what was wrong with me before the diagnosis (I felt I was being treated like a timewasting hypochondriac by my GPs and didn't want to go back), and I spend up to £200 a month on supplements that I need just to function as well as I do. Now, with a GP who doesn't believe in Lyme Disease and a negative ELISA test, I don't feel that returning with my positive Armin test is going to help get me any useful treatment. I am looking at travelling to the US which will obviously cost many thousands. Actually, I am looking at taking my daughter with me. She was diagnosed with sarcoidosis 4 years ago, and has since been going downhill healthwise unsurprisingly since she has been on steroids and methotrexate. She is only 38, and has 2 children. When I realised that the bullseye rash I had before all my symptoms was Lyme disease, I remembered that my daughter had had one similar before her own symptoms. The doctor in New York skyped with her, and believes that Lyme disease probably underlies the sarcoidosis. She is having the Armin test next week. Meanwhile, she has seen numerous Consultants, from Endocrinologists to Rheumatologists, had MRI scans, lumbar puncture, biopsies, drugs galore and several days in hospital... which would probably have paid for her treatment in the US several times over...

Loss of partner

Inability to fix up flat and sell it and loss of rental income in meantime

Loss of friends/social life

Unwell / pain / exhaustion every day

Loss of income and progress in career (selfemployed)

Basically my entire life has stalled or gone backwards relative to who and where I was a decade ago. I've been desperately unwell for 10 years AND now I'm 50 instead of 40.

The part of my life where I expected to get married / have children has been taken from me with little prospect of that ever being a possibility again.

Lyme Disease has destroyed my life. 5 years ago I had an Oxford scholarship, and choral award, was predicted a first class degree and had the offer of Masters places at Cambridge, Oxford and the Courtauld. Despite my best efforts to battle this disease (before I discovered what it was) it eroded my ability to study, to work, to play my instruments, to paint and even to walk. By 2013 I was housebound and generally sofa bound all my energy was gone and I could no longer do any of the activities I loved. I could barely read. Since my diagnosis in Autumn 2014 I initially saw great improvements with treatment, but having had the infection for over four years, treatment has been slow and difficult. My late diagnosis means I might never fully recover, and yet at the time I was bitten I went to my doctor with the erythema migrans rash, and a few weeks later went back with an unseasonal flu which is utterly indicative of the first stage of Lyme. This was ignored and now I may never get my life back. At the very least I will have lost over half of my twenties to this debilitating disease.

Lyme disease has affected my whole physical, social and emotional wellbeing beyond belief.

Can't drive, can't walk, can't leave the house unattended, can't sleep, weight gain, heart issues. Family life ruined. I'm a hermit now.

My quality of life is a shadow of its former glory. I am mostly housebound, I am mentally and physically affected and therefore cannot work, function reliably or enjoy any aspect of life like I used to. Socially I am severely limited, I'm limited in my everyday activities to simply survive and exist, to eat, clean and do the necessary treatments to get well. I have lost any chance of a foundation for my career due to being unwell for the majority of my twenties and now entering my thirties wondering if I'll ever be able to have children or not be dependent on careers or outside help. I've

lost almost a decade to this disease thanks to the lack of knowledge in treating and recognizing the symptoms in the NHS & denial of its chronic form.

My interpersonal relationships have been severely affected, damaged due to this disease and the lack of available treatment and acceptance of its existence through the NHS. Financially my family has been burdened and the cost of paying for private treatment has been in the thousands.

But the worst part is having your brain taken away from you overnight, knowing something was wrong and being misdiagnosed for 5 years by the National Health Service. From pillar to post, from doctor to specialist, test after pointless test and most turning around and saying they can't do anything for you lets hope it gets better on its own. Having to figure out what was wrong ourselves whilst unwell as the answers we were being given were never quite right when the patient themselves requested that infections were further looked into, but the testing in this country is abysmal. And being sent to a psychiatrist because their cocktail of drugs weren't getting me well. Which yielded nothing for either party.

So getting tested doesn't mean a thing it stops people from investigating the real cause as they're told they're negative. And once you do figure out the cause there is no available treatment so you're left to rot by the NHS and told you cannot have chronic Lyme disease even with a CDC positive igenex test.

If my previous quality of life before Lyme was a 10, it is now a 2. It is a daily struggle. The symptoms are devastating, and the lack of medical support is worse. It is traumatic, serious and life threatening. I have hope through a private Lyme literate doctor and if it weren't for them, I don't know where I'd be now. I've hardly used the NHS' facilities in the past 12 months because I have been told nothing can be done for me with a Lyme diagnosis prior to that I had endless blood tests, xRays, MRI's and prescription medication which most likely was more harmful than good. As well as CBT which I felt was unnecessary and not helpful. The cost to the NHS and to myself personally and the change to my quality of life have both been huge.

I can only work because I can do so remotely otherwise I would not be working. I went parttime as I was too tired. Lyme has robbed me of the fit body I had and my social life and friends. I sometimes still have to go to bed early and I wake up tired. My parents (aged 70s) had to help me with basic everyday things because I couldn't function. I look really, really well and I feel so ashamed. I continue to improve on long term antibiotics, antimalarial drugs and around 38 vitamin supplements a day which are *incredibly* expensive. Lyme has cost me tens of thousands of pounds and I haven't even calculated the lost income of parttime work.

Yes : Autism

What quality of life!! I have none! I was a working professional for many years even after my first bites in 1993 in USA with 2 big bullet rashes, while 2 mths pregnant with my son who was then born sick (maternal Lyme transmission) he was born with a VSD hole in heart & many other problems needing open heart surgery he's now a sick adult joint pain ME/cfs Alan MacDonald pathologist found VSD's as a defect in pathology of babies infected with borrelia. Diagnosed with Fibro, EBV & ME in 1995 I struggled to work all my life sick a lot compromised my career & promotions. 2006 cancer struck from HPV virus and me having a broken immune system still fighting it today! 2009 bitten in my garden at home in wilts went to doc told ringworm! Then become too overwhelmed and sick to work never worked since continual new diagnoses and new symptoms Never heard of Lyme until Rheumy wanted to test in 2014 this is where my discovery began. I don't have a life in bedbound 97% of the time all last year was spent in bed only left home to go to GP or to hospital. I'm a single mum no family with 3 kids.. Who all need testing but I can't afford it! My oldest son had Lyme ELISA ve on NHS in Dec 2015. I want a life I want my independence and career back I can't afford treatment and I have tried go fund me and failed at raising anything other than testing funds. I'm only 43 but live the life of a 90 year old. Despite this I have tried to help with campaigning was involved with 2015 patient conference at

Parliament and the fight now Lyme campaign all bought about by patients we are desperate! I don't want to die of NHS undiagnosed, untreated Lyme disease, things don't look good for me as my organs are starting to give up one by one. And I'm waiting for yet more surgeries my 28th was July 2015 think how much I could have saved the NHS alone by fixing me properly!

Lost career, friends, family, dismissed by doctors & accused of having mental issues. Isolated & socially shunned & ridiculed. No understanding or support whatsoever.

I've been so terribly ill, own my own business

entertainer

was also keen fitness weight training always been healthy hard worker who loves life happy married with 2 X children , over years it's getting harder for me to live, take care of my girls walk the dogs

I want to work more but it's so debilitating, pain excruciating I've pushed through as I love my job but as times gone on I can do less now I can only work 2 to 4 hrs and by doing so I suffer days of chronic pain , takes 3 to 4 days to recover,

heart palpitations

meningitis

chronic fatigue

dizzy Ness passing out

neck back.pain

psoriasis immune system disfunction

widespread joint pain

many other syptoms

in hospital due to Lyme and getting ill weaker, and legs giving way, I don't want to be in a scooter but soon I may more than occasional when severe ,if I'm left untreated heart failure organ failure I cannot afford to be treated elsewhere private as due to loss earnings I'm lucky if I can eat

we need testing accurately in UK on nhs for Co infections western blot for Lyme.
doctors need to be given updated info that shows them how to treat and help patients;
Dr horowitz has written done many recent 2016 research on Lyme and Co infections he
treats people all over the world and written many papers that it should be a new law
the follow up and learn about not from the 1950s the nhs guidelines are based by
doctors need to stop dismissing patients with real problems and giving them anti
depressed pills when there clearly suffering because of the disease and yes the pain
makes you feel down but this needs treating via the co infections as we dont want to
be left in our bedrooms for days due to being so sick!

I do not claim benefits

I'm too proud and independent minded and determined to beat thus I don't want to be
labelled disabled I want to be able to play with my children dancing, working,
living a full life just given pain relief and not treating the illness or listening to what the
patient says, I have many on going symptoms worsened over years left untreated due
to Co infections and Lyme, been treated disgustingly left to suffer in pain!! I'm unable
to go out with friend lost many friends. It truly does disable you with pain
one min you look normal walking next on the floor .

better awareness more funding Def needed,

better diagnosis, I have lost 3 years nearly four of my life gone spent in out hospital nhs
misdiagnosed me many times and continue, had I been treated earlier and asked
question have you been abroad or in deer areas UK I'd say yes had they have asked was
i bitten I'd have said yes, diagnosis would be reducing years of pain suffering and
treatments that are ineffective as I was suffering with Lyme disease, not once even
though I displayed all symptoms of Lyme was I asked in nearly 4 years was I bitten have
I been abroad? do I have mould in home or other so I could have treated diagnosed
faster

I have had to do a buy to let to get out of my home where I caught Lyme Disease the GP refused to tell the council there was a Lyme problem. I told the council they insisted it was a nice problem.

When I believe it was a electro pollution problem killing off the ecology and killing the tick predators. So the Tick multiplied.

The government close radio communications agency in 2002.

The Railway industry have complained their equipment does not comply to EMC LAW.

I went partially blind at work when I was 27yrs old. I was bedridden ever since. I am now 44yrs. I have sent letters to the Prime Minister asking for treatment so I could get back to work & stop having to claim benefits. I have wasted limited energy appealing to PCT 3 times, who kept losing my file, so as to delay things. Then I appealed to CCG. I am single. I lost the chance of having children, finding love, having a career, making a difference with my voluntary work. I went from a sociable, outgoing young person wanting to make a difference in the world. To a bedridden, suicidally depressed, suffering manias, paranoid, agrophobic, too scared to answer the phone person. I did not just lose my health & my mind... I lost ME!! Complete personality change. I lost many friends & family members, as they did not understand. They believed the NHS, as in their minds, if the NHS says you don't have Lyme Disease, they are the "experts", they "must be right." You lose relationships with people that call you lazy, because you LOOK ok. Instead of being an outgoing, fun loving, caring person, I have turned into a lonely, isolated, depressed, could not care if I died person. I was so positive before, I was called Polly Anna. So I've gone from PollyAnna to the Grim Reaper. I find it hard to be around myself!!

So the worst thing I have lost, is ME!! How do you cope with a situation & chronic illness when you are not yourself. When I get a glimmer of myself, it brings a tear to my eye & I literally say out loud "I've missed you!!" If I cannot walk, I can cope with that. I can cope with pain 24 7. I cannot cope with NOT BEING ME!! The mental torture is the worst. 18 years feeling someone else, that you do not like, is torture.

I've lost my past, my future & myself. ?

I had my own small business, which provided a part time wage as well as having a capital value. When I became ill, I was unable to continue, and lost my customers as a result. I couldn't sell the business on as I was too poorly to cope with the handover. So my business simply folded. I have lost the part time wage it gave me, as well as the possibility of a lump sum in selling it on.

My husband and I had a savings account with around £15,000 in it, which we hoped would help us in our retirement. This is now empty, the majority of it being spent on medical bills, and the rest to prop up my husband's wage for dealing with one off expenses (such as car repairs etc). We now have no safety net or financial security, though we are just about keeping our heads above water on my husband's modest wage (less than £30,000). It's a struggle to live and still find money for my medical bills. My family have been incredibly supportive, but if I was on my own then I would have given up long ago. Socially and emotionally, lyme has affected me hugely I don't like socialising and have lost all my confidence. I tire quite easily so can only do socialising in shortish bursts. I'm much better emotionally than I was I think I cried practically every day for the first 18 months or so, and felt totally wretched, helpless and broken. The fact that the NHS was so completely dismissive and unhelpful was just yet another battle I had to fight, but barely had the strength for. I still find it difficult to cope with stress or confrontation of any kind, as my symptoms flare and I just can't deal with it. I also have brain fog and dizziness, which is very difficult to live with.

I would like to get a part time job to help with the bills and also for my own sanity, but it's hard to apply for jobs when I know that some days I wouldn't be able to make it. But on my good days, I feel I could be doing something.

Most of my friends, with very few exceptions, have drifted away and I no longer hear from them I have received far less sympathy and understanding from them than they would give to someone with a more recognised illness . . . I think they think I'm making it up or something, as some days I look fine, but they don't see me on my bad days.

Lyme has changed me and my life in many ways, and none of them good. I feel like a shell of my former self sometimes I used to be bright and witty and chatty, but now I have totally lost my confidence and my "sparkle". However, I am improving and, in many ways, I know I am lucky compared to how badly affected many Lyme sufferers are.

My life has been devastated, turned upside down and bears no resemblance to what it was before. I was a fit and athletic person with a sports background and outdoor career. I was a newlywed and about to start a family when Lyme hit. I am now unable to exercise, my husband and I have had to postpone family planning, I have been traumatised by the illness and subsequent lack of support from the NHS. My family have had to fundraise for my treatment and I fight everyday for my life back and cling on to the hopes and dreams of a family one day. My life and my husband's have been decimated! We struggle emotionally, financially and spiritually everyday. We have been tested to our limits and at times have nearly given up. I have been in this fight 4 years now and at the age of 34 I am worried about our future and losing everything we ever worked for.

I continue to work, although it is a struggle, and my husband and I continue to contribute to the system and society but we have had nothing back. We have felt abandoned, redundant and worthless on many occasions and life has truly been taken away from us. I fight for myself, my husband and my family. I fight to hold on to our hopes and dreams and I fight so that others can see that recovery is possible, but we should never have had to do this alone! My heart has truly been broken by Lyme and all that it has brought. Ripped from life by the bite of an insect. It is still just so hard to believe. Things have got to change!!

At the beginning of this disease after mosquito bite I was weak, I had pains, it took me long time to get back to myself, I am still not symptoms free after 8 months of taking antibiotics, taking herbs, being on the special diet.

It is constant worry will I be able to do as much as I used to, I am getting tired quickly, some days I feel that I cannot be bothered to get on with life.

It has completely ruined my life. I dont feel the same person. I cannot function. I cannot do the same things. I used to be a bodybuilder and now my neuro symptoms are so bad I can barely get through the day.

I am in debt because of this illness.

It has devastated my life. I had to give up teaching in a school. Most of the time I am to I'll to go out. My parents have to help me a lot with daily chores like cooking, cleaning and ironing. I have my own tutoring business which I would like to expand but am too ill. Just this January I have lost £750 from cancellations. I also had to recently turn down a part time job in a school due to my health.

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Reduced energy level and has reduced my useful activity

8 years ago I was perfectly healthy, since then my issues have come in phases and meant at times being bed bound, unable to work. Over the last few years the neurological issues have become terrible, uncontrollable twitches, burning constantly in my hand and feet, repeat flu/cold every 4 weeks. I have also since being ill had 2 children whom i barely get to spend any time with as when I'm well i work, when I'm ill I'm in bed, this has put tremendous strain on my relationship with my wife. I also run a successful business with my business partner however he has had to do most of the

work recently and has even suggested i leave the business, which i've spent 10 years building, because they cant rely on me

I have no life, I am in constant pain and mostly housebound,

Financial difficulties, no quality of life

At my worst, the hypersomnia meant I needed to sleep 1520 hours per day just to function. I regularly (daily) had bouts of intermittent paralysis, I kept losing my voice, I couldn't stand or walk more than 3 minutes at a time, my stomach couldn't tolerate most of the foods I grew up with (gluten, corn, certain fruits and vegetables amongst other things). I developed a terrible heightened sensitivity/intolerance to light and certain smells but the worst symptom is still the hyperacusis (noise sensitivity) which is so bad that I cannot bear many normal everyday sounds (such as the Hoover, washing machine, kettle, certain musical beats, a fly buzzing around the room or a toddler crying/screaming amongst other things).

Am unable to progress in life any way. Any spare cash that we have is not being spent on our children or saving to buy a house but my healthcare privately which includes costs of flying abroad accommodation etc. My partner has to take lots of time off to look after children because I can't.

My extended family are now suffering financially. Social services have been involved because of me suspecting my children also have The disease and doctors not agreeing. It's disgusting and inhumane, The info that is being published on the NHS website about this disease is making us look like we are mad. The results are catastrophic, life is a constant war in all directions. People with illnesses have some sort of haven through medicine or knowledgeable consultants we have nothing.

I'm a stay at home mother, so work wasn't a concern from the beginning. However, the longer I've been denied care, the worse off I've become. I have trouble raising my child and it affects her and my husbands work. My husband has become my career. I can no longer enjoy the things I use to; like ice skating, going for bike rides, taking my daughter to the park, travelling, being a once very active mother.

We are starting to feel the financial strain as we have been paying out of pocket for supplements and medicines.

I use to have a social life but that has ceased to exist. I have lost many friends, as no one understands and it's hard to get out and do to much.

I'm only 28 and I feel that I'm at the end stage of my life.

Fatigue pain and cognitive problems affected my career as a lawyer and I was pressured to resign from my job.

I still suffer significant joint pain and some fatigue which compromises my activities.

I have only been able to actually live a quarter of my life...for thirty two years. The rest has been in a brain fog, body pain, constant crushing headache. Constant lethargy makes living properly impossible.

After writing about 1000 words, here it is in brief. But I would always elaborate if needed in future.

Ruin of my first marriage. My personality changed, I was too tired to do anything at weekends, too tired to do anything on holidays. Getting more ill, I was divorced by the 3rd year.

Because I'd begun a new job shortly after the tick bites, my new colleagues never knew what I was like before, and I could feel that they were becoming more and more intolerant of my illness.

Loss of my house which I bought after the divorce, as I became too ill to work ever again by the 5th year..I've had to rent, first private landlords, now a housing association, since 1993.

Loss of my career. Loss of the ability for fast intake of knowledge and the confidence of being bright and fast in my thinking.

being treated like a moron by doctors, as if I was a stupid woman, depressed and mentally ill instead of being in pain and utterly weak and exhausted to the point of collapse.

Loss of being able to enjoy music, and any loud noise is painful. Loss of ability to move fingers properly to play guitar

I used to be a mean dancer, was very athletic, loved squash and my hobby was going up mountains.

Inability to go to social clubs like the ones for the pensioners around here. Or any of the clubs, or church events.

Gradual loss of family contacts, I couldn't travel to see my young nephews growing up. Its now 10 years since I was able to drive to see my elderly parents. They have had to come and see me, thanks to one of my brothers driving them 250 miles, but they are now too old to travel. I miss seeing them deeply.

My own child had to suffer relocation 5 times before he was 5 years old. Each new address meant new people around us. Some places were furnished, others unfurnished. Its not so friendly in East Anglia as it is in Stoke or Manchester people keep to themselves more and are suspicious of strangers. I should never have moved here, but was under the belief that ME was all due to stress so rural seaside location seemed a good idea. I got worse over time.

My greatest sadness is this : my son got amazing A* grades for his A levels, but I was too ill to go to parents evenings most of the time, and so poor it was impossible for him to go to the Oxbridge open days, or to think of applying for a degree there. He had to choose a university near to home, and it wasn't the best subject either for him. My illness has affected his life, and I don't know if I'll ever get over that.

During his childhood, (he is 24 now) we had 3 holidays, thanks to the help of my sister in law caravan holidays in the UK. I feel sad often about my life, but the impact of this invisible illness on my son is the sharpest pain in my heart

We have both been socially ostracized, even by my nearest relative in this area, one of my brothers who lives 40 miles away, who was the reason I moved from Manchester, 300 miles away, to this area.

I should have gone from Manchester back to my parents really, near to Stoke, once I'd sold my house, but they said its best to go and live near to the sea, and your brother will help you out, and his sons are the same age as your boy..

But my brother has instead always looked down on me, and told people it was all in my head. So have other people around us. Its only now, in the last 6 years of the 30 year illness, when I am almost totally disabled, that neighbours and family have cottoned on to the fact of how ill I am. I have to have carers they are paid for by Suffolk County Council, but some of my DLA is used to pay for it as well.

I manage to get my self dressed and so on, but they come 3 x a week to make sure I get out of the house, if I am well enough. My brain is so foggy and the pain so bad, quite often, they cannot take me out, but do things like food prep or ironing instead.

What a waste of my life ill since 1985. What a waste of my degrees (3 of them) and what an impact on my son if only I'd known that ticks caused illness, if only the GPs had known back then...and the NHS test for Lyme I had in the fifth year, if only that had been reliable.

My quality of life is very poor. I mostly need to use a wheelchair. I had classic EM rash at 4 years. I was told by GP that my test was negative and I needed no treatment. We later discovered that the tests had been positive all along. Whilst I was relatively healthy for a few years, I had problems with my back and knee and various other issues, which the GP refused to investigate. I crashed fully at 18 and was refused a consultant by 2 CCG's who insisted my problems were psychological. I only managed to attend university once in the final year. My work is all done from my bed. I cannot

socialise, I cannot exercise and I have very few friends now, as they have all dropped away. I have told my GP that I feel they have dug a hole and placed me in it, putting a lid over me. The impact of Lyme is massive and my life has been devastated in all areas.

No work, social life, etc

Reluctant to go out socially, having to give up job due to memory problems making to many mistakes

Lyme disease has had a truly devastating effect upon my quality of life.

Four years ago, I was bitten by a tick at Centerparcs (Thetford Forest) whilst enjoying a break with my partner and young children. I was an energetic, healthy, happy person enjoying my family and social life and working part time in the City in a job that I loved. I am 40 this year and my life today bares no resemblance at all to this.

I am still employed but have been unable to work for the past 6 months and all sick pay has ended. I am reliant on my partners salary and ESA to pay the bills and fund my medication and treatment. Due to the Winchester Lyme clinic closing we are also financing a trip to the Jemsek Clinic in Washington DC next month by remortgaging our home. I hope to be well enough to return to work following treatment at the Jemsek Clinic and although it is a large financial investment for us as a family we cannot afford to wait for the situation regarding treatment for Lyme disease in the UK to improve. I have a job to get back to, bills to pay and a family who need and want me to be well as soon as possible. I am also desperate to have my old life back!

I have been too fatigued to have any social life for the past three years. I have to live in the moment and can't make any plans from one day to the next as my symptoms are so unpredictable. On a good day I can take my children to school and then come home to rest for the day. On a bad day I can't walk up the stairs, shower or leave the house. I had to stop drinking alcohol and follow a gluten/sugar/dairy free diet of unprocessed

food so eating out and socialising is awkward and less enjoyable when you can't eat or drink like everyone else.

The effect on my family life is the most upsetting. I have two energetic young children who I want to play with and take care of. They are missing the well version of me and currently don't believe that I will ever get better. I am regularly presented with home made Get Well Soon cards that break my heart and rarely have the energy for play dates or trips out to the park. It is not my children's fault that I caught Lyme disease and they are undoubtedly suffering as a result.

My partner is juggling a full time job and commute with most of the childcare, school life and housework and has no time for a social life himself. We have lost touch with so many friends and family as we can rarely go to social events and few people know what to say or understand the lifestyle of someone with chronic illness. Each day, we are putting one foot in front of the other, just coping and surviving. It is not a quality of life that I would wish on anyone.

Lyme can be totally invisible to people outside of the family unit. I am sure that many of our neighbours have no idea how limited our quality of life is by my illness.

I have been given a terminal diagnosis of ALS at the age of 33, despite lots of other symptoms not consistent with this, including meningitis. I have a two year old daughter and I'm struggling to cope with this.

I'm now in America spending up to £100,000 in an attempt to save my life.

I can't walk unaided, I'm losing the use of my right arm and hand, I'm in pain, having seizures and life is unbearable. I can no longer look after my daughter and I have to be cared for 24/7

The NHS does not support my decision to go to the US for treatment and have said 'Lyme can't cause my symptoms and there are absolutely no indicators I have Lyme, and I'm the riskiest patient they have ever had seeking treatment and I should accept my terminal diagnosis and concentrate on enjoying this last time with my daughter.'

I was a well, happy, proactive and sociable undergraduate with everything to live for and great work prospects at the age of 18 when I got sick. I managed to get my degree despite constant infections, fainting and no energy where I was often bed bound. I have had to drive my own health investigations every step of the way as every doctor I saw was either baffled or didn't believe I was ill. It has been me researching everything. Nobody ever mentioned tick bites or Lyme, despite me saying I had been in the jungle at one point and had had many insect bites (no rash). I didn't even know what Lyme was. I had no diagnosis at all for years despite the fact I was so sick I could hardly work (just 23 hrs a day some years) doing something relatively menial...then eventually not work at all, passing out a lot, resting for most of the day in silence as that was what helped, losing my social life, having to move back in with my parents, not being able to hold down any kind of relationship, spending lots of my savings and my family's savings trying to get a diagnosis and get well. Eventually at about age 26 I was given a CFS diagnosis but I kept saying it didn't really fit. From that point onwards most doctors dismissed my health complaints as part of CFS and I met with a lot of preconceived negative medical judgements re the validity of CFS. Outrageous really. Comments how a young girl like me should just get on with life, stop wanting to be ill, get a boyfriend and a baby, go clubbing. All when I was virtually housebound with obvious signs of infections...all because the doctor had made up their mind about me on hearing the letters CFS before I even stepped in the room or started to explain my current issue. I found NHS doctors so unhelpful I stopped going and would just write a letter if I needed anything. I went to private holistic clinics instead to try and treat my symptoms. They kept telling me I had some kind of infection but whenever I asked my GP or medicals doctors to test for some common CFS related infections they refused. On calling up my medical records it seemed I had not had many infections checked for at all over the years. Under 5. Then I had what I now think was a second tick bite from a nymph here in my garden in South London just 5 years ago. It was tiny with a prong attached into me. Mum had a similar one in the garden years before with a bullseye rash. The GP had given her anti biotics for 5 days but never mentioned ticks or Lyme.

We have lived here since I was little so I could have been infected here before. My symptoms got worse and new symptoms popped up. I had not had any treatment as there had been no rash and I didn't know it was a tick. I started twitching and having jolts at night, I developed tachycardia (I do not suffer from anxiety). I started feeling even weaker and was getting more and more infections. My hands and feet started to burn. Insomnia got worse. I went to A&E as my GP had no idea what was going on....and neither did any other GP in the whole practice. However I was sent home from A&E as standard tests were normal.

Eventually I paid to see an Endocrinological Surgeon in Chelsea with an interest in unusual misdiagnosed conditions in any field. He was German and flagged up tick infections as he had some experience. We sent my tests to Germany and they were antibody negative but Elispot positive with a low CD57 showing immune suppression (thus possibly explaining negative antibody results). He also suspected I have more infections but I am saving my limited money for treatment. Proper lyme doctors diagnose clinically and don't rely on possibly flawed testing.

So how has lyme affected me? Well you can see I am now unable to work, I live with my parents at the age of 42, I get no medical care actually related to my tick infections, the cause of my illness, and I have developed loads of other associated issues that have sprung up. I am too sick for a relationship, I have missed the chance to be a mother now and that breaks my heart, I am in constant pain and have constant symptoms, we don't know if I can ever tolerate treatment due to complications from very late diagnosis (c20 years), I can't eat a normal diet, I spend all my money on supplements to try and keep me as well as possible and I basically have very little social life or much to look forward to. So as you see this story has shown how my life has basically been totally ruined in all areas. I am a naturally optimistic person so I will see what can be done in the US or Germany or wherever I have to go for treatment once we can pull together the money but it looks like I will be dealing with these and possibly more problems for life now. I can see how people commit suicide due to this situation in the UK but I am a fighter so I will not do this.

And yes I do blame the lack of medical awareness and the arrogance of doctors and flawed testing and treatment by the NHS for a lot of my troubles. Basically what has occurred is professional incompetence and gross medical neglect from a very senior level all the way down to a lower level. Even the nurses make negative comments when the doctor pops out of the room. You will be fighting a whole culture of stigma here. As soon as I went out of the UK for medical advice my condition was picked up on quickly. All my dealings with overseas lyme doctors have been incredibly helpful and professional and they have been in complete agreement with all my own conclusions about my health. It is all completely understandable to them and they provide medical and clinical evidence to validate all conclusions. Lyme doctors have even come to the UK to spread their knowledge in recent years and their help was turned away. Frankly it embarrasses me to even be British when I hear about how the medical authorities and government have handled this illness and those closely linked. I don't know how certain people sleep at night. It could all so easily be prevented too! It's crazy. The situation as it is must be costing the UK government millions!

I am now 90% well due to privately funding treatment through BCA in Germany and I continue to improve. In the year before treatment my quality of life and that of my husband and children was dreadful. I was no longer able to work and as I was self employed I did not have the benefit of paid sick leave. My children, then 12 and 14, had to witness their mum climbing the stairs on hands and knees, sleeping for big chunks of the day and I required them to take over household chores. It was heartbreaking to step back from the role of being a mummy. I couldn't pick them up from school in bad weather, meals were ready made and burnt and I stopped attending parents' evenings as I feared my jumbled speech and odd walking made me appear drunk. They were frightened and I had no explanation to give them of what was wrong with their mum. My husband lost his sociable, organising and fun loving wife. I rarely left the house or got dressed. It is a testament to his love that we have made it through this dreadful

illness and that he investigated Lyme and supported me in that diagnosis when the so called UK expert, Dr Dryden, said I didn't have Lyme.

Im too sick to work . I have lost all my friends. A lot of family members. I have no life its been totally destroyed.

Ongoing issues with joint pain and inflammation. Chronic fatigue. Neurological issues such as memory loss, motor tics and myoclonic jerks. Frequent inflamed sore throats.

It has ruined my life my financial situation, my career, my family life and social life. I've had to raid my savings that I was hoping to use in retirement, to pay for IV antibiotic treatment in Belgium. I still need further treatment but I can't afford it at the moment.

I had to retire early from work and as I wasn't diagnosed with a specific illness I couldn't take early retirement for medical reason. Therefore my pension monthly payments to me have been reduced because I broke my contract.

I've missed so many family occasions from being to ill to attend. Whether it's weddings, christenings, family holidays, meals out, visiting a new home/apartment. Lyme has robbed me of these fun times, these memorable times, these close times, these bonding times.

Most of my friend have drifted away. I have become very lonely and isolated. Some of the problem is because Lyme is not understood or accepted. People think you are being dramatic , a hypochondriac , attention seeking. They think all that's necessary is to pull yourself together.

An example of this is when I went to the CAB for help with filling out the forms for attendance allowance. The lady that was helping me had never heard of Lyme, when I said I spent several days per month in bed, her reply was we all have days in bed that doesn't entitle you to claim for AA.

If seems to me that regular people and people in responsible positions can't help being judgemental about things that they don't understand.

This disease took away my life at age 45yrs until then I had BROUGHT UP 3 SONS AND DAUGHTER (ONE PARENT FAMILY) AND ALWAYS WORKED. Initially I could not get out of bed due to exhaustion and pain. It has left me unable to join in family outings and ruined my social life as I used to be very outgoing and social. As for finance I cannot believe the stress I have been through in claiming benefits. (have also used up money that was left to me in my mums will)(it is only through my determination and support of Kirklees cab that I carried on for nearly 6yrs fighting the DHS. I had such high hopes that once my children left home would start a business taking homeless people in and had already started to do this but was not to be. I cannot believe the attitude of the magority of NHS doctors

Outward appearances suggest moderate health, good finances and happy family. I am actually an emotionless zombie. I don't feel human. I'm contemplating suicide.

Where do I start, I was an athlete and I'm not now. Exercise wipes me out. I have cognitive problems and recal problem. For years I had nerves pain down the right side of my body with joint pain. I had a variable sensitivity to alcohol but couldn't understand why two glasses of wine would make me feel and sound like I've drunk a bottle. I lost my drivers licence as a result off one glass of wine as the body wasn't processing it. The cops were confused as I seemed fine. They pulled me over cause I had a boot on my foot from a broken toe. I lost my job as a result. Subsequently I've found out why that was happening. I had to change jobs 8 months ago as I couldn't cope with the stress of commuting and being office bound, I looked awful. I was ask taking medication for Lyme at the time. I now work from home which is a god send but I'm still forgetful. My relationship has taken strain as I can't do things with him I would like to, he has endless energy. Herxing quite badly and been weepy as a result which

isn't easy to be around. Not to mention the ironic anxiety now about getting the right treatment.

I used to be a store Manager in retail with 11 members of staff working for me for 4 years. One night I went to bed and the next morning I couldn't walk which was in 2010 and my health went down hill like an avalanche . It's be ongoing since then with all sorts of issue I never experienced before .5 years later my joints are on fire, I can't empty myself unless I have my legs up on chair , I don't wee properly , my memory is so bad I can't even spell or speak French very well . My feet feels like I'm walking on fire they are that sore 24/7. My eye vision is terrible I get scared at night time if I'm a passenger in a car , I live like a recluse because I don't function on a normal level . I have random scratches or stains that shows up on my skin after having a shower or bath out of no where , my tongue is so huge from the inflammation going on inside me . I have a liver disease which plays up like a yoyo and the attacks can b so bad I ended up in an ambulance on several occasions . I don't go out unless it's my weekly shopping with the help of a friend/ family member . I see my grand child rarely as I can't cope with loud noises . My life is just pure misery and how I'm still here is because of my children .. My house is my sanctuary and has been for 5 years and if nothing changes then that's where I will b for a very long time .

My quality of life has changed enormously because of the range and severity of symptoms, many worsening over time. I was a sociable person, but have few friends where I live because of my being unable to go out to meet people and then often being too unwell to keep arrangements for coffee etc with the few friends I have made. Any social arrangement made, including holidays, carries the pressure of being worried that I will have to back out; in fact we have had to cancel three planned holidays on the past two years. When my illness became particularly bad, I had a young child and while my husband was working, it was extremely hard for me to look after him and see that my son didn't suffer because of my situation. As I cannot walk far, getting him to

things and giving him exercise was difficult, as I could never run around to play ball etc. I also was exhausted mentally from trying to teach and stimulate him and give him a normal life. I have a degree in English from a top university (Durham) and a postgraduate certificate in education. I am sure that I got Lyme whilst I was still teaching, but I have never managed to regain my health because of the very late Lyme diagnosis and treatment.....so I was too ill to consider any sort of job once my son went to school. This seems a waste of my potential and has had obvious effects on our earnings. It has also been very hard for me to pursue hobbies, in particular I have found reading difficult because of the concentration, memory, malaise and fatigue issues which are part of Lyme: since I am an English Literature graduate, this has been a bitter blow, although I do persevere.

I am a graduate and had a career which I loved. 27 years ago I suddenly became ill and was eventually diagnosed with ME. I have not been well enough to work since then, so I have missed out on the income a career would have given me. I have not been able to live my life and have missed out on the possibility of relationships and family. I reached the point where I could no longer walk or care for myself, but no doctor was able to find the reason for so many years of illness and debility. I never stopped searching and eventually private overseas testing gave me the answers borrelia, Cpn, yersinia, ehrlichia, EBV and CMV. I am gradually making good progress with private antibiotic treatment, but, even with these test results and the obvious improvement with antibiotic treatment, I am not able to access any treatment from the NHS.

I have missed out on most experiences; social, educational, personal, etc since I was 10 years old. I'm unable to work or study at university. And unable to look after myself most of the time. I have missed out on my childhood, and am now going into my twenties pretty much housebound. I rarely leave the house, when I do its in a wheelchair. I cannot remember what it feels like to be normal/healthy. I have lost a lot of friends, and have had to deal with a lot of prejudice and disbelief from family,

friends, teachers and doctors. I was misdiagnosed for 10 years. I am now paying out of pocket for treatment abroad. This has all affected my close family, physically and mentally.

My life has changed completely. Went from very physically able to work, exercise, walk the dog, help elderly relatives to then being in a wheelchair, mobility scooter and using a walking stick. Without antibiotics, am in severe pain, cannot tolerate sound, light. Nausea balance problems. Cannot walk unaided. Cannot leave the house independently, spend most day lying down. Torturous headaches and neuropathic pain. Deep bone pain in major joints.

Got Lyme at the same time as obtaining my degree at University and have never worked since then.

A typical month will consist of:

56 days with extended periods in bed (1820 hrs/day)

2530 days unable to get up in mornings

2025 days when I feel bad but carry on

34 days when I can get out but not travel too far

0 days when I can consider doing anything strenuous

0 days cycling or exercising etc

0 days further than 20 miles from home

I am too poorly to work, my condition is very unpredictable so impossible to commit to a job. Very hard to socialize as I feel so poorly so much of the time. Some friends have not been very understanding about this, it's very hard for people to understand when you look well. I am fighting to get better, and since a few months on doxy prescribed by the Dr did not make me better, I had no alternative but to seek help privately. My father is currently funding a herbal protocol.

I was made redundant from my job as an art dealer as I could no longer do the job due to Lyme. I wasn't entitled to benefits, so I have had to live off savings while trying to gain free lance work I could balance with my level of illness/ disability. As I slowly got better, the last couple of years, I have been able to just about sustain myself but won't be able to work full time. I lost my contract as a semiprofessional bike racer and after two knee operations and with severe degeneration of the cervical spine, I will never be able to race again. Lyme disease and the damage it has done have been life changing. I have had to spend my life savings and increase my mortgage to support myself and pay for treatment. I have gone from being comfortably off to barely sustaining myself below the poverty line. I am now retraining as a medical herbalist to help others get better and it will be a job I can do within the limitations caused by Lyme.

My family lives abroad and I have been unable to visit for the last 5 years, even when my mother was suffering with cancer. I no longer have an active social life as years of illness and lack of mobility had me pretty much house bound.

I haven't worked since 1989 and I am now of retirement age. I have been ill for 30 years and I am virtually housebound. I am not well enough to cook or clean. Sometimes I am too poorly to take a shower and I am bedbound for part of each day. I am in constant pain with my head.

Mine was an outdoor lifestyle, gardening, DIY, my two young largebreed highenergy herding dogs came with me as I worked very long hard hours as operations manager in a demanding international fishing industry. I was a hardy, robust woman who never had a day off sick, ever! I was sociable, cooked fine meals for family, friends, colleagues I was invincible.

After tick bite a GP denied EM, I deteriorated & cognitively unable to judge my own health until family intervened 2½yr later. I continued to work but lost my job through incapacity five years after the bite.

I no longer garden it's a wilderness now,

Work unemployable 65+, I managed a small company but can't manage my own finances now, DIY house in disrepair.

I'm able to walk my now older dogs a short distance.

I live between my bedroom & kitchen, two rooms are closed as I can't maintain a whole house. I never socialise at home, rarely go out in the evening, ostracised from prior colleagues & some friends, certain family members misunderstand my difficulties, I've never walked my grandchild in the pram or bathed & put to bed.

Instead, I fight to get well, fight GPs and fight the NHS and all because a GP didn't recognise EM and refused me a course of antibiotics costing less than £10.

I have virtually no social life. Lost contact with friends, been unemployed for 4 years. Struggling to survive on one very average salary. My chance of having a family of my own has been taken from me as I'm 38 years old and still ill due to doctors not listening to me and being fobbed off during the first three years of my illness. My illness has affected my family and husband who financially support me but now my own husband may be made redundant soon. I've lost any chance of studying and getting a career. My life has been taken away from me but this illness has prevented my husband from succeeding in life too.

It is soul destroying.

Affected me mentally as I am not so sure this "thing" is ever going to leave me, it's terrible knowing so little about it and thinking that it's beavering away in the background. Thankfully I have a wonderful GP but I always go to see him thinking one day he is going to label me neurotic and that in turn adds to the pressure. The pain in my joints has stopped me doing the things I love and the things I do daily that we all take for granted. It hasn't stopped me lifting the kettle but it takes 2 hands to lift half a kettle of water now. Madness. Can't bring the logs in for the fire and I hate asking! I can't garden and that is my first love. I have had to give up the gym, can't pick up my

grand children, can't turn the mattresses on the beds blah blah blah. Stupid things I know but so annoying. Shopping is a bind now too. Can't carry too much for too long

I have a BSc and MA, I had a professional job in the public sector, an excellent salary, great colleagues. They kept my job open for 2 years after I became sick, I was told I was a greatly valued member of staff, but I was never able to return. I had an active social life, a hobby which meant I travelled all over the country. Great family life, parties, socializing with friends. I am unable to do any of those things now. I struggle to have short visits from even my closest family. I never see friends now. I have been unable to drive for several years due to vision issues, vertigo etc. My husband gave up his job, he also had a professional career, and is now my fulltime carer.

I have had no income since becoming unwell. I was bedridden for the first year. I lost my job and could no longer care for myself on a daily basis so moved in with a partner. Their income meant I was not eligible for ESA benefits. I was too unwell to be able to deal with applying for PIP and by the time I was able to, I was deemed too 'well' to be eligible.

I've been unable to work for nearly 5 years now and completely reliant on my partner financially.

When it was clear the NHS were not going to help me I pursued private medicine and have spent over £20k to date, of my partner's money and money that I fundraised. I'm still unwell, although have a better quality of life than I did at the beginning. But it takes considerable input from private and alternative medicine to maintain this small quality of life.

All of this could have been avoided if I was diagnosed and treated promptly, instead I was continually fobbed off with being told I had 'a virus' that would clear up.

Realistically, I would love to get better and work again, but I'm unsure if I'll ever be well enough. I'm 31.

My life has changed in every possible way. I am unable to walk more than a couple of hundred yards now and the arthritis has severely damaged all my joints. The Lyme has also attacked my nervous system so now I have POTS, dysautonomia and MCAD which means I have bad reactions to most rheumatoid medicines and find it very difficult to stand for more than a minute or so. Luckily I can work from home, so my mind is occupied at least. Otherwise it would be a very dull existence as I don't leave the house unless I have to, which is usually for medical appointments. I have two beautiful kids, but having them put a huge strain on my body and has meant that my health deteriorated faster. Fortunately I don't have any depression but I do worry about my future and my ability to get around my own house and take care of myself and my family.

Financial cost £500,000£600,000 (cost of treatments, care & discrepancy between potential earnings (assuming NO career advancement) in the 23 years unable to work. Total loss of the ability to pursue a career & earn my own living. No social life outside of the home as I am predominantly housebound & often bedfast. Loss of a normal married life. I have never been well enough to start a family & my husband is now my carer. Total alienation from my family who still believe that I cannot be ill if the NHS are not treating me. Loss of all the hobbies & activities I used to enjoy, & I have not been well enough to take a holiday, even in the UK, for 17 years. Loss of independence I can do longer care for myself without significant help. 24/7 severe intractable pain that is not responsive to medication. Whilst my contemporaries are planning their retirements, I'm planning my final exit and funeral as the day will come when my husband & I are no longer able to manage my care at home.

Retired early from Civil service on grounds of ill health, after nearly two years of Incapacity benefit. Unable to walk up or down stairs for 3 1/2 years due to muscle weakness and joint pain in every joint.

But recovered my health to near normal on long term antibiotics prescribed by GP who has been open minded and treated empirically after reading much of available science that is emerging.

have given up my job after 23 years therefore I am now reliant on my husband. I also have been told that I cannot receive benefits due to lyme disease and horrendous tinnitus

I have no social life due to the mental health symptoms this disease has given me. I cannot go to cinema, theatre, restaurants, public transport, gym, zumba, walking 12 miles a week, holidays and travel, don't drink wine anymore, I decline social invitations to weddings etc which I always enjoyed, discos where I danced all night but not now. I have lost many friends due to not being able to go out with them and I very rarely go out of the house.

I am unable to support my family and visit them. They are very worried about me and feel helpless.

I have passed lyme to my daughter in utero. She is very ill and unable to work or have a life she's now 27. I try to take care of her but I'm too tired and ill myself to either have a life myself or take care of her properly.

I am constantly exhausted and can't take part in activities, social life, work, eat things that I'd like to can't even walk my dog.

I try to make the best of it but it's a struggle to stay positive with no outside help from anyone. Not even being able to talk to the doctors for fear of ridicule again.

My husband also has lyme so I've probably passed it on to him as well. It has ruined our life and our family life and we are struggling without any help. My husband's lyme has affected his cognition badly and he's showing all the signs of bvFTD (dementia). We are relatively lucky financially because my husband, also unable to work, has a finally salary pension that we live on.

I have no life. I am unable to leave the house the majority of the time and when I do go out I then have to spend the next few days in bed to compensate. I feel much worse when I go outdoors. I can't do anything with my children and often can't even string the words together to have a coherent conversation. I have no relationship with my husband as I'm so ill and I have had no social life for the last nearly 3 years. I spend the majority of my time reading Enid Blyton books as my brain is so befuddled that I'm unable to comprehend anything else. For varying periods of time I can't get out of bed. Some days I feel better than others but these are unpredictable so I can't plan to do anything. I want my life back!

No longer able to work. No longer able to do any physical activity for more than a short time. Struggle in social situations due to hypersensitivity to noise light etc. Isolation. Bullying. Losing independence. Unable to give family support they need.

Destroyed my families life

I was a confident, successful woman making a contribution to society in many ways including having a high earning job which contributed to GDP.

Now I am a shadow of my former self. I have spent years feeling unwell and struggling to get a diagnosis. I've spent thousands of NHS, private and my own money. I'm no longer able to contribute to society. I can't work full time. I can't do charity work. I can't do the things I used to which put money into the economy. I have virtually no social life, it's affected all my relationships. I'm unable to try for a baby.

It affected so many elements of my health brain, heart, joints, eyes to name a few.

I'm a positive, intelligent person who has been proactive in getting a diagnosis and treatment. I also have a very pragmatic and understanding GP but her hands are tied by NHS guidelines. I feel even more for the people who don't have the intelligence and finances to tackle this themselves. It's a silent killer.

I thought I would die, every muscle, bone, organ in my body hurt, shocks and twitches, feeling that I wasn't getting oxygen, panic, complete left sided numbness from face to foot, a thickened mitral valve in the heart, chronic sinusitis, larger than normal brain particles, memory loss. After five years of high dosed antibiotic therapy, chelation of heavy metals, Chinese cupping, rife and infrared sauna, almost full recovery.

Lyme disease has made it difficult to carry out everyday tasks and be involved with family life. This obviously has a knock on effect to other family members.

My world has come tumbling down since my positive result, for chronic Lyme I am physically and mentally exhausted, I can't drive anymore, I can't look after myself anymore, I'm aggressive to those who care and who are trying to help when they too are battling their own problems, I am in constant daily pain. I have no quality of life and there is no positive light at the end because doctors don't/ can't help as they no/so little experience with this deadly disease. I'm having to self treat myself with no guidance, the NHS should be ashamed.

I have no quality of life. I need full time care , for 11 years now. Diagnosed with M.E 11 yrs ago. Numerous Lyme NHS tests negative until I saw Mr Caudwell on TV.

Immediately sent bloods to Germany came back positive for chronic Lyme and co infections. Devastated that this suffering could of been stopped over a decade of my life I have been misdiagnosed and mistreated by healthcare professionals who believed there was nothing wrong JUST M.E.

I have seen hundreds of doctors specialist now with these blood results i still will get no help in my own country . I have to go to America for specialist care as I'm so ill this will be very hard and financially difficult on my family.

it has left me physically emotionally, mentally Spiritually and financially , Broken

Private diagnosis and treatment has cost me over £33,000 not including travel costs up to this point.

I am a full time carer for my wife and so the work must be done, so 3hrs/week cleaning cost for the last 5 years and over £12,000 in carer costs over the last year, plus stress major stress and fatigue.

Quality of life destroyed, fatigue, sight and hearing problems. Cognitive function problems mean I cannot pursue my hobbies. I have difficulty shopping and making change. Difficulty speaking and communicating. Get lost when driving, Confusion and memory problems most of the time.

I have been ill since I was 20. I have never been well enough to work full time or have children. I haven't had a career and have no family of my own. In my 20s I was too ill to leave the house on a high dose of beta blockers with no way of accessing information about their effects. Doctors were rude, arrogant and dismissive. I found out at the age of 28 what their true effects were, weaned off them and was able to get my first job 3 afternoons a week.

With no way of explaining to anyone why I was permanently ill I had to struggle on until last year with no knowledge of my true condition. Imagine that. Even people with cancer can explain why they are ill. I never could not even to myself.

Ten years of steady decline in health , visiting many Doctors and Consultants to no avail. Now cannot go out on my own notsteady enough. Cannot walk very far and have resorted to using a wheelchair on occasions. Sometimes laid up for days.

Husband is 70 and still working in order to pay for private treatment. Socially dont go out much and had to give up my interests, i ncluding golf, gardening and yoga. Have to pay people to do gardening and house cleaning. Cannot help with looking after Grand children when member of family was very ill and they had to pay for help.

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Devastating effects on family life and health. Added to that, being insulted by doctors and not being believed has contributed to and compounded the effects of this insidious illness.

From being a formerly active, healthy, industrious, tax paying, law abiding citizen to a physical wreck.

I'm paying for antibiotics as part of my private treatment so it's caused a huge financial strain on our income. Ive also paid for private Lyme tests abroad and then there is all the supplements and healthy food I have to buy.

My family life has changed as my condition means I am no longer able to be the fully functional wife and mother that I once was.

Lyme affects you financially, physically, emotionally and mentally!

My earning power has been taken away and all financial independence and contributions to the economy. My parents have had to fund my private medical care. My social life has also been severely restricted and my life is plagued by a wide range of symptoms daily which affect my enjoyment and participation in life.

I became ill at 26 years old and am now 58 yrs ? Lyme has ruined by life .I was unable to have children as too exhausted and ill to look after them. Only got a positive Lyme diagnosis 4 mths ago after over 30 yrs of being sick. My father had to support me as

unable to work and am now spending my inheritance from him on private medical treatment but am still very sick due to being misdiagnosed with for so many years

I'm a single father of three children. One autistic one pandas. My whole family Lyme and co infection positive. Also I have two men I employ doing building maintenance. Coping daily with this all has severely impacted on my health very detrimentally it's a daily battle to get through he day

Pre Lyme I used to earn 28k in a full time job and loved walking my dog and going on social outings. Now, I'm off work sick, unable to walk my dog or leave the house to see friends. My GP mentioned that Lyme disease does not exist in the uk and if I had it, I'd be dead by now! Hence why I left getting tested via Armin for a long time thinking I did not have Lyme even with part of the tick still inside my leg. No antibiotics offered as the Armin test is not approved by the NHS. As I'm typing this with funky vision and numb hands I just feel angry, ignored and ashamed to be English. I am currently raising money so I can get treatment in America which annoys me further as I should be getting treated in my local hospital just two miles away but instead I have to travel thousands of miles with great financial expense.

I used to be an active member of my community I set up and ran a community group for mums and babies as a volunteer. I worked voluntarily on the National Breastfeeding Helpline, taking two or more calls a day.

I was a busy mum to 4 children and also worked part time in a job I loved, to help pay the bills.

I haven't worked now, paid or voluntarily for 7 years. The financial strain on the family has been great we had some years where as a family of 4 we lived on less than 10,000 pounds a year we got by by growing vegetables and my husband, as well as his job working with children and young people, chopped and sold firewood.

It has put a huge strain on our marriage and on my husband he has to look after me, work full time (he has more than one job to pay the bills, look after the house and take the kids everywhere they need to go and attend school parents evening etc. I use a wheelchair and have no independence at all. I haven't been out on my own in years. I had to give up driving and as we live in a rural area there is no bus service, and anyway there is no one apart from my husband to push my wheelchair. My youngest daughter doesn't remember me ever being well all she wants now at 12 is to go on a shopping trip with just me and her and we cant do that.

I CANT SUPPORT MY FAMILY IN THE WAY I WOULD LIKE. My mum has been in hospital but I cant help her at 77 she still helps me! I have two grandchildren now and cant help with them either. I have no social life, no friends and have lost a lot of my confidence. I used to be a busy, happy outgoing woman. I don't know where she has gone.

I have been ill for over 20 years, 18 undiagnosed. It has effected my whole adult life. At 24 I attempted a degree in midwifery and had to drop out due to health issues after 9 months of hard work. Every time I have tried to get a career going or better myself it has fallen apart because my health can take it. I tried to do a degree in health promotion 7 years ago and became very sick after only 4 weeks and had to leave the course. My diagnosis and treatment comes from a private Dr in Europe and this has caused us to get into debt. So far I have spent about seven thousand pounds on private Drs and treatment etc. Even my MCAS wasn't dx but the NHS I had to go private to get help for the awful symptoms I was having. The Dr I saw does work in the NHS, but as I live in Wales I couldn't be referred to him there are no Mast cell specialists in Wales. The NHS also dx me with EDS(H TYPE) BUT THEY HAVE OFFERED ME NO treatment or support at all I was given a leaflet and discharged. I cant afford more treatment privately we had to borrow the money from the bank and now we are going to have to sell our house that was our dream place that we built ourselves (with organic gardens and forest). Because I have been left so long with an incorrect dx I have now developed Mast cell disease this means I cant tolerate antibiotics or herbs s treatment

f Lyme and co is very difficult if not impossible. I may never be able to recover. I am 46, I cant imagine living the rest of my life like this.

Destroyed my business

Loss of friends

Distrust from family because the "professionals" know better than I do

Constant pain

So exhausted all the time from just existing and trying to get well

Social life too tired to go out in the evenings, and limited social life at weekends.

Financial debt due to depression retail therapy.

Family life Struggled to stay in long term relationships thus unable to start a family

Devastated. Lost good career, family, friends everything. Now trapped at home. No career, no holidays, no socialising, no sports. Constant pain and disability.

Financially it has cost us in the region of £50,000. I have had my relationship with my partner tested, I've been unable to look after my young child full time and been very restricted in the activities I could do with her. I've had to more or less give up my previous pastimes of mountain biking and mountaineering. For a long time I had no social life as I was almost house bound and unable to make plans. I became socially isolated. I am slowly rebuilding friendships now that I am recovered. My trust in the medical profession and authorities has been shattered.

From being an active, intellectually promising, Oxford student with good prospects, the outcome of my degree was affected, I spent two years struggling with study and employment and for the past two years I have been economically, socially, physically and intellectually inactive. I cannot shop, socialise, study, work, or do housework. I am in constant pain, varying in intensity, depend on my boyfriend to support me

financially and depend on my parents and other family members to fund my treatment. I spend all my time waiting for the occasional "good" day when I have the physical and emotional strength to paint.

I can't work, I can't study, I have no social life, I can't exercise. I'm DESPERATE to be well enough to go to London in the autumn to start my degree at Birkbeck.

Its devastating. I WANT to be well! I WANT to be productive and have my life back! I WANT and NEED help and treatment for a treatable, hopefully curable disease which costs far less to treat, than costing millions due to dustbin diagnoses, or do we in fact make people more money by staying sick?

My life has been devastated by Lyme Disease. I'm now reliant on a wheelchair to get around, and have lost my business due to feeling so ill. I'm unable to work and can't see how this is ever going to change. If it wasn't for my husband working all the hours God sent, I would be completely reliant upon state help.

yes, i have really bad joint pains, my brain fog and memory are scaring me, my eyes are getting worse by the day, the tinnitus is sending me mad, i have skin problems at sight of bulls eye rash, palpitations, panic attack, agoraphobia, and so on, make it really hard to keep going, but as i said i have to work to cover bills, and keep a roof over my head, not easy, i have to come home and go to bed at about 6pm to be able to continue and have at least two days a week in bed, to stretch and rest and do exercises for joints, i have trouble sleeping with pain sometimes and spend the night crying, a lot, but i fear taking pain killers, as i truly believe it is best to know what pain you're in, and if i started to take them now and had to up them each year within a few years i would be a pain killer zombie i try to fight that, i'm hoping to be able to keep working and save for a test from germany, and hopefully some kind of treatment eventually,

Where do I start? I lost my job and career, I was production manager in a food factory and would have risen to site manager eventually. I lost a good salary. I lost my mobility, most of my friends and the ability to have a normal life. For 25 years I have lived as an invalid, old fashioned term but it's how I feel. I did manage to get treatment seven years ago which restored a lot of my health for five years until I was bitten again three times. My LLMD is no longer allowed to practice in the UK. I started my own business when I recovered but I am now unable to do that most of the time and what I do I have to have major help. I was earning £30,000 pa twenty five years ago, this would have risen as my career progressed. Instead I have existed on benefits for most of the last 25 years, hand outs from family and friends. I am lucky I just managed to keep my house but spent most of an inheritance on treatment and then subsequently having had to bail out my partner who had an accident and whose insurance failed to pay out on a technicality. The injuries he sustained were not sufficient to keep him in hospital for longer than three days at a time despite him having seven operations, a severe head injury and four fractures. At the time the insurance was taken out those injuries would have been covered but advances in medical treatment meant they were not. Had I been working it would have been less of a strain. My partner was unable to work for four years by which time all our savings were gone and I had to be the breadwinner with my small business.

I bitterly regret the toll this illness has taken on me and my family. I am not able to have a normal social life, in the past I was an avid walker, gardener and traveller. I have lost all that. I can't walk and have no energy to do anything else. My weight ballooned due to being on the wrong medication for seven years and I have been unable to lose it partly down to the lack of exercise. I now suffer the social stigma of obesity to add to it all.

To sum up because of a tick bite twenty five years ago I have not fulfilled my potential in the workplace, have not fulfilled my aspirations and hopes for the future and have had a long, hard, painful road to where I am now. The future without treatment now I am almost retirement age looks equally bleak. In short I lost my life because of Lyme.

Loss of earning potential, social life affected, loss of independence.