

Paul Bramble And My Story

My name is Paul Bramble and I have just had the worst years of my life, but now I hope I'm looking at a much brighter future. This is my story of how my life changed for the worst and how I had to overcome the ignorance of certain sections of the medical profession. I had to board a plane not once but twice while semi paralysed and fly to Germany to have the relevant tests done that would prove to all once and for all that I had Lyme/Borreliosis, because in my own country doctors refused to accept the word of one of their colleagues. The medical profession refused to consider that I could be suffering from Lyme Disease/Borreliosis even though one of their own had dared to suggest it.

How It All Started.

On the second of October I married my long time partner Niki and it was one of the happiest days of my life, apart from the birth of our children of course. We had been together 12 years so it was about time that I popped the question, as our boys were now 4 and 6.

We had our honeymoon in Romania and stopped in Prague on the way back. In Prague I fell desperately ill. We both thought it was a bad case of food poisoning and although I nearly had to take a later flight, we didn't think too much about it and put it down to one of those things.

When we returned to the UK, I went to the doctors just as a precaution. While sitting in the waiting room I noticed a small lump on my left arm, it looked like an in-growing hair so I thought it wasn't that important and didn't report it to the doctor. I hadn't noticed it while we were away so I didn't give it another thought.

What Was Happening To Me?

Towards the end of October I noticed something was wrong with me. I played football for a local team and was well known for having a high stamina during heavy games.

During my first game back after my honeymoon I noticed how tired I was. At half time I mentioned it to the manager of the team and he put it down to eating and drinking while on honeymoon and of course a lack of training. At the back of my mind I had a feeling that there was something else wrong.

The next week I worked hard in training to see if I could get some of my fitness back for the next game. I found training very hard work. I couldn't breath properly and found myself doing short runs then having to stop to catch my breath. This really was unusual as I had only missed two weeks of the season and while in Romania I had done a lot of running through the forests and I had even been bear trekking with a local gamekeeper.

The next game was worse than the first. I just couldn't run. I was so tired that at half time I begged to be taken off as a sub but the manager thought that a whole game would do me good. Halfway through the second half, he had no choice but to take me off, as by now I was at walking pace. My wife and I put it down to a virus that was going around.

November was a hard month for me, by now I had stopped playing football and I was aching every morning. I had a light flu that I couldn't shake off and I was starting to find myself getting very snappy with people at work, but I was sure it would all pass.

December bought depression; I had never suffered from depression before so I didn't really know what it was. I new something was wrong with me and now I really was starting to worry. My eyes had an increase of what they call floaters but a visit to the Opticians found nothing wrong with me. My doctor's visits were getting more and more frequent I had blood test after blood test but they found nothing wrong with me. Was I going mad?

We have two dogs and I used to love walking them over the fields by my house, as we live in the countryside we don't suffer from the usual light pollution that stops people from looking at the stars. I used to love my time looking into space and wondering what's out there? During one of these times when staring into space I could tell there was something wrong with me, sometimes you just have a bad feeling and this was one of those times.

On Christmas Day while watching my children open their presents and with the excited smiles I wondered if this was my last Christmas. By now I was convinced I was dying. My wife Niki was thinking the same but kept it to her self.

January and by now the aches and pains were getting so bad that I was finding it hard to walk. I was starting to struggle at work and now I was starting to feel tired all the time. If I touched alcohol, it didn't matter how much, I had such a bad hangover the next day it was unreal. I started to go home at lunchtime and sleep until the next day but wake up as tired as the day before.

February and March are months that passed me by. My aches and pains were now unbearable, and although by now I was constantly tired I couldn't sleep at all at night and yet I could sleep standing up in the day. During the past months I had lost over two stone in weight. I was now so down that everyone was starting to worry about me at work, especially my mother who worked with me running the Catering dept at Twycross Zoo.

Am I Going Mad?

At last a diagnosis, the doctors told me I had shingles! I was told by the doctor, "There is nothing serious wrong with you". So it must all be in my imagination. Because in my head I was feeling so ill I felt like I was counting down on the days I had left on this earth. Many people may think it all sounds like I'm exaggerating, but those who have been through or those that are going through this will know what I mean. If you are one of those going through this don't give up, remember others have trod this path and it does get better with time and the right treatment.

I was now starting to have headaches, they were just like the ones you get when dehydration sets in but no amount of water would shift them.

The months rolled by in a bit of a blur, I was visiting the doctors nearly every week but still clinging to the Shingles diagnosis and the doctor telling me it would pass.

September and I actually started to feel a little better, I really did feel like I was over the worst of it. My aches and pains were going just like the doctor said. November and I was talking about getting fit for football again. At last it was all getting better I could look to the future again and see my kids growing up as I was convinced I would miss out on that.

December I had a new optimism about the future all was looking up. My Mother had been in hospital for a heart operation but was allowed out for Christmas.

Everything seemed as if it was getting better. My illness seemed a thing of the past and my Mother was looking brighter with each day that passed. Things were looking up at last. Life was good again.

Collapse

January 2nd is a day I will always remember. It was the saddest day of my life. My Mum died.

She suffered a massive heart attack in the night. Just the day before she had looked so well. I, as well as many people who have been through this, remember how I had the news broken to me. I was at work in the office when I had the call, it seemed as if time stood still as the news was broken to me. As I have said I worked with my Mum everyday, we ran the Catering at Twycross Zoo. I found it hard to take and spent the next few days shutting myself off from the outside world.

I know I am not the only person who has gone through this but the effect it had was for me to shut myself away and hope that it would all go away, I even had those mornings when I would wake and just for a second it was how it all used to be, until I remembered that it all was true and the reality was painful and hard to take.

My Mums funeral was to be held on the 12th January, I know it seems like a long time after the death. We wanted an early service so we didn't have to worry about the night closing in around us if we had it too late in the day.

January 10th was the day I decided that I had to face the world again; no more shutting myself away, my Mum wouldn't want that.

I was watching TV in bed till about 10:30am when I noticed what seemed like the vertical hold slipping and the picture on the TV going funny for a second. I thought nothing of it at the time and got out of bed and went to make a cup of tea. Whilst the kettle was on I ran a bath, I was going to clean myself up and go to work to see everyone, because it was a loss for all the people at work as well as our family. While in the bathroom I felt the floor move just for a second. I went downstairs thinking that it was odd but nothing more. I made my cup of tea and went up the stairs to have a good soak in the bath. While drinking my tea and walking up the stairs it happened again, the floor seemed to move making me take a seat on the stairs, again it soon passed. And I carried on toward the bathroom when my phone rang in the bedroom - it was work. This was when I noticed that I was slurring on the phone. I hung up and went to the bathroom to look at myself in the mirror. I looked ok and was feeling ok.

Whatever it was I still didn't feel it was anything too serious. I got into the bath and then it all started I couldn't stand. I felt like gravity was getting it's own back for all the years I had taken it for granted. I was now fighting to keep my head above the water while I tried to take the plug out with my left foot as the right one had lost all coordination.

I managed to slide out of the bath, how long it took is all a blur now that I look back. Now I was convinced I was dying. My children were at school and my wife had gone to see friends, I was alone and scared my face was numb down the one side, what was happening to me? Then after what seemed a lifetime but I'm sure was only a few minutes it started to fade, I managed to drag myself to the bedroom naked and soaked.

Niki arrived home to find me gripping to the end of the bed calling her for help; it had started coming on again worse than the first time. I was slurring to her to help me but what could she do apart from call an ambulance? She was trying to comfort me when it seemed to pass and I could stand again. I put on some tracksuit bottoms and an old t-shirt.

The ambulance arrived and after an inspection they said that they had not seen anything like it before. It was like a stroke but a stroke doesn't come one minute then go the next.

They were treating me on the bedroom floor because we have very narrow twisty stairs and they didn't know how they were going to get me down them. After a few minutes I could walk down the stairs myself. One minute I was walking and talking the next I was a mess on the floor unable to stand. As time went on the attacks got worse and worse.

In the hospital A and E department, the first doctor on the scene diagnosed me with Vertigo and told us not to worry. Niki and I didn't agree and I told the doctor he was wrong.

The doctor looked in my eyes as if to play along. He waved his finger in front of my eyes for me to follow; he actually stepped back at what he saw and rushed off to get another doctor for a second opinion. My eyes were working independently, one stayed fixed while the other was rattling around my head.

After a couple of hours I had four doctors looking at me, they had no idea what was wrong with me. I was now thinking allsorts of things. Was this it? Would I ever see my children again?

I was moved into a different room for a lumbar puncture. As I lay there I could see the worry in my wife's eyes she looked tired and scared, I could see the doctors gathered around whispering and looking confused.

After the lumbar puncture I was advised to drink coffee or cola to help prevent the onset of a headache. Niki gave me a cup of coffee, but I couldn't drink it from the cup. It was then that I realised that I had little control of my facial muscles. I had to drink my coffee from a straw! It was about this time that my body was growing tired and my eyes were too heavy to hold open. I wanted to stay with my wife but my eyes grew very heavy. I tried to fight it but I was losing the battle. I remember they started to move me, but on the journey to the ward I finally succumbed to unconsciousness.

Emergency Assessment.

I woke in ward 3; it was an emergency assessment ward in Burton-on-Trent hospital. Most people are on this ward for a day or maybe two - I was there for weeks.

When I first woke I remember a nurse gently shaking me and calling my name. I couldn't move, speak or see properly and my eyes were still very heavy. I soon went back to the darkness. I'm not sure how long I was "out" for but I do remember coming round and hearing my wife telling the doctors that I was going to miss my Mum's funeral. She had tears in her eyes and all I wanted was to hold her and tell her I was fine, but I knew that I wasn't, well actually I didn't know anything. She asked if they knew anything yet, but the answer was 'no'. They still didn't know what was wrong with me.

I couldn't lift my head from the pillow, let alone my arms or legs from the bed. The doctors had nothing.

One of my most vivid memories of this time was when one morning I woke in the hospital. As I opened my eyes, which were still blurred, I saw through the window an elderly woman walking down the corridor to make a visit to someone on the ward. The way the lady walked, although still blurred to my sight, I thought my mother was coming to visit me; she would make it all right. My mother always made it all right. She would have some answers; mum would tell me I was going to be fine. A warm glow came over me, that feeling of being safe now. As the lady walked past my bed and to the man in the bed next to me, that was when I remembered my mother had passed on and I really was alone and now very scared. I had never faced anything in my life that was serious without my mother there to tell me, "Everything is going to work out fine".

After a few days I was able to sit up in bed with the aid of two strong nurses. The whole of my right side was paralysed, my sight was blurred and when I tried to speak all I could do was slur. My wife and the nurses had to do everything for me. Niki would be there every morning to take me to the toilet. She would shower me and shave me; she bought me fresh pyjamas every morning. Niki had to listen to me as I cried.

The doctors were stumped. I had MRI scans and CATT scans. The scans did show a shadow on the back of my brain but that still wasn't enough for them to know what they were dealing with.

While lying on my bed one morning, dribbling and paralysed, my doctor visited me to tell me what it wasn't, but not what it was.

I was told it could be Guillam-Barre with Miller Fisher syndrome; Multiple Sclerosis or it could be a virus or Chronic Fatigue Syndrome. In short they didn't know.

Dr Griesz- Brisson.

I was hoping to get some treatment, then one day they told me they were going to give me a course of steroids, and I was to have this treatment for a few days. Luckily for me on the night of my first steroids treatment, a neurologist visited me.

She was a German lady called Dr Griesz-Brisson. She asked me questions about my illness and about my past illness. She asked about my "shingles" and she asked me if I had ever had a bite or a mark on my body that I couldn't explain.

I remembered the in-growing hair on my arm when I was sitting in the doctors after my bout of food poisoning after our Honeymoon. I told her about all the doctors over the past year and how I had felt for the year. That was when she said it. "You have Lyme".

I had never heard of this and was shocked at what she was telling me, but I also felt relief, although it was short lived. Now you would think this was a diagnosis? You would think that now I was going to get all the treatment and care that I needed? But that was not going to happen.

Lyme Disease/Borreliosis Diagnosis Denied.

Lots of doctors came to see me, most of the time they had as many student doctors as they could fit round my bed. But all these doctors had the same thing to say to me and that was that "it's not Lyme disease". This was in front of all these students so what are they going to diagnose if they cone up against someone in the same situation in the future?

All the doctors apart from one (Dr. Griesz-Brisson, Consultant Neurologist) told me that I didn't have Lyme disease. Even the doctors in Nottingham who had taken an interest in my case said it wasn't Lyme disease.

A doctor in Nottingham told me I had a stroke, but this was months later and I will get to that later.

My breathing was monitored daily as I had been having trouble with it, but as time passed I relied on my oxygen mask less and less.

My world had crashed down around me, all the things that I took for granted like my wife and children even going to work they were all gone. I couldn't see past this and it was wife that kept my spirits alive in the early few days.

I didn't want anyone to see me in the state I was in, so at first I wouldn't have any visitors not even my children. I didn't want them to see their dad in this way. It really was a mistake to shut them out because their little faces were one of the things that kept me going. My wife was fantastic and was there for me from morning till night.

As I have said, Niki dressed me showered me and even took me to the toilet I couldn't do anything for myself. All this time the doctors did nothing.

One night I remember being propped up in bed, whatever position I was placed in was the way I had to stay in the early days because of being paralysed down the right side. In the bed opposite me was a man called Cyril. He had looked very ill most of the day. As I was propped up, all I could look at was Cyril as he was in the bed opposite. I had to watch him die. I tried to press the buzzer for the nurses but couldn't reach at first; I had to wriggle my good side till I was in a position to get my finger on the button. It took 25 minutes until a nurse came and found the body.

I don't blame the ward nurses; they were fantastic and are under valued by the NHS. They had four wards to look after at night and there aren't enough of them, many of them are over worked. In the case of Cyril they were busy with other patients. All in ward three were observation patients, most were very ill and needed a lot of care. So few of them can't help everyone when they are busy with other emergencies. I thank all the nurses on ward three for doing all they could for me while the doctors did very little.

Dr Griesz-Brisson was treated like a crackpot behind her back. When I asked the doctors what it could be, all they would say is "Its not Lyme Disease/ Borreliosis so get it out of your head". Dr Griesz-Brisson stuck to her guns and convinced me she was right. I didn't know what to think but I had to believe in something. She was the only person I felt I could trust. I had to trust someone.

As time went on I started to feel like I was in the way. I wasn't getting any treatment and the doctors had hit a brick wall. They wanted to transfer me from Burton on Trent where I was to Nottingham. The dates for the transfer kept changing and I was losing my faith in the NHS. Slowly and after a couple of weeks in hospital and getting less than adequate treatment I decided I wanted to go home. By this time I was on what seemed like the Geriatrics' ward!

After a couple of days the doctors allowed me to leave. On the day I was leaving I had a visit from another doctor, this time it was a doctor from Germany who was in England to give lectures. One of the things she was here to do was educate English doctors to the dangers of Lyme Disease/ Borreliosis. This doctor was an American doctor working in the Laboratory in Germany that provides the blood tests that are needed to give a full diagnosis of Lyme Disease/ Borreliosis. She was called Dr Valentine-Thon. Dr Valentine-Thon [lead author of the paper entitled 'A novel Lymphocyte transformation test for Lyme Borreliosis'] examined me and came to the same conclusion as Dr Griesz-Brisson.

She told me that without the correct treatment it would happen again. Would this not be enough for me to get the correct treatment?

She asked if any tests had been carried out. The answer was, of course 'NO'. Simple tests were overlooked, even when Dr Griesz-Brisson had given a diagnosis, her colleagues didn't do the tests.

(The routine tests in the UK carried out on me for 'diagnosis' of Lyme/Borreliosis was negative.)

They had started to pump me full of steroids, and then stopped on the first day into a 5-day treatment. Why was this? Even with a second doctor telling them it was Lyme disease they still wouldn't treat me!!! This was really the day that I realised how ill I was.

Leaving Hospital.

I left hospital that night. I was walking with the aid of sticks, was very unsteady on my feet and it was like watching the world through a very small portable TV. My sight was still not perfect, although my eyes and brain had got used to the hospital lighting.

It was dark when my friend arrived to pick me up and I struggled to get into the car because I couldn't judge distances very well and kept on banging my head while trying to get in the car. On the way home was when I realised that my illness wasn't going to be just for a couple of weeks. The front lights and brake lights of other road users made my head spin and when we arrived back at my home I was feeling very ill. My children were waiting for me to give me a kiss and a cuddle. I could see the worry in my children's eyes; I could also see the tears.

I spent the next few days feeling the worst I had felt since it all began. The movement and the lights on the journey home had taken their toll. I felt like I was going to die. I was desperate to get some treatment.

Readmitted to Hospital.

On about the third day home from hospital my condition worsened and a doctor was called out to me. He checked me over and insisted I went back into hospital. An ambulance was called and back I went. While in hospital I was told there was nothing that could be done for me. They told me that they needed the whole attack to happen again so they could do all the tests that they didn't do in the first place! I was so scared now. I couldn't go through it all again. They kept me in because they wanted to monitor my breathing, but the next morning I left without asking. It was obvious to me that they did not have a clue. I still wonder how long it took to notice I was gone.

This was the pattern for the next few weeks. I had another night where the local doctor came out to see me, she was very concerned that I wasn't getting any treatment and was more than willing to help me. At last there was a doctor that was willing to help me. At last there was a doctor that wanted me to get better instead of one wanting me to have the attack again.

She was a young doctor, Dr Mecedo, she wanted to help me and not just sit back and see what happens. Dr Macedo happily researched Lyme Disease/Borreliosis and spoke to microbiologists and Dr Griesz-Brisson for advice on medication. Dr Griesz-Brisson couldn't prescribe any medication, as, until I had visited her day hospital I was still a patient of Dr Palejwala (my consultant in Burton). Dr Mecedo prescribed me my first antibiotics, and within 3 days I could feel the difference.

Germany.

I visited my Consultant Neurologist Dr Griesz-Brisson who advised me that the only way we were going to get the hospital and other doctors to listen was if I could get my blood to Dr Valentine-Thon, in Bremen, Germany. The lab would do the appropriate test, the MELISA test (which is not available in this country), and confirm the Lyme Disease/Borreliosis.

Dr Griesz-Brisson gave me the equipment needed, including syringes and even the jiffy bag. Dr Macedo agreed to take the blood but unfortunately, the NHS would not pay for the test or transport the blood- so my wife Niki got to work to organise the couriers.

Easier said than done!! Not one courier would take my blood. Dr Griesz-Brisson's secretary even phoned around a few hospital couriers for Niki, trying to organise something.

The only answer was to fly to Bremen myself. The expense was not an issue, as we desperately needed to know what was wrong with me. Was it Lyme or not? I know I had been told that it was but there were still doubts in my mind put there by the NHS.

I had to know once and for all so I could start getting my life back together.

It was now March, and although I was feeling better due to the antibiotics I was on, I still didn't feel well enough to fly. It was the only way I was going to know for sure what was wrong with me. I still didn't know for sure whether it was Multiple Sclerosis, so I needed to go.

By now the strength was returning slowly to my leg and arm, and although sleep was rare, due to pins and needles and aching, I was going to bed usually around 7:30-8:00 o'clock.

I was booked on a flight to Germany on the 20th of March 2006, though still feeling like I should stay at home in bed. Thanks to my friend John Ray, who took me to Germany, I had my tests done on the 21st March.

At the airport on the way back I felt very ill and just wanted to be home with my family. I was on antibiotics and Amitriptyline for my aches. I was diagnosed with Fibromyalgia as many Lyme Disease/Borreliosis sufferers are. The Amitriptyline did help me.

The results of the MELISA test came back from Germany inconclusive because the antibiotics I was taking had interfered with the results. I had to come off my medication and go back to Germany. It was now getting very tight as far as money was concerned and to top it all I had to be off my medication for a month before I had my tests.

My friends were all supporting me and without my friends I would not have been able to make it through.

A Stroke?

In April I was called into Nottingham hospital to have a second opinion. In the waiting room I was feeling quite good, it was one of my better days, in the cycle of Lyme Disease/Borreliosis. I was sitting with my wife making jokes when they called me in to see the doctor. (Nearly two hours late).

Again it was full of students waiting to see the great doctor at work and learn all they could from the master. After he inspected me and let all the students inspect me he gave his diagnosis, "You have had a stroke", he said. My life came crashing down. I went from feeling fairly good to feeling depressed within seconds. This was by far the most arrogant doctor I had the misfortune to meet. Well if he is teaching then we are all in trouble.

Confirmed Diagnosis- Lyme Disease/Borreliosis

I rang Dr Griesz-Brisson for advice and she told me I had to go back to Germany for the MELISA test again and get the diagnosis. Luckily for me, my work, which had supported me all the way through the illness, said they would pay for me to go to Germany. This meant I could get diagnosed a lot quicker. I still had to pay for the tests but not having to worry about the price of the flight and accommodation was a lifesaver. I am very lucky to have the job I have and to have people that care.

Again I went to Germany to have the tests I needed. This time I was able to fly no problem at all. I still had to have John with me, as he wouldn't let me go alone, just in case. This time the results came back positive and now I had to get the treatment I needed.

Dr Griesz-Brisson gave me some supplements from Germany, which I had to pay for, Blue/green algae and extra strength omega 3. Because of the results of the MELISA test, I was able to have my antibiotic treatment given to me on the NHS. The Enoxaparin syringes and Cefuroxime Axetil tablets changed my life within days. I have completed my third course of treatment now and I am no longer on any medication. This MELISA test and the treatment given to me by Dr Griesz-Brisson changed everything for me. I am now back at work and leading a normal life.

Conclusion.

I have tried to be brief in my story and I have not told everything, as it would take up too much time. My spelling and punctuation isn't great and I still struggle with the computer screen and some words. I am getting better and it took a German doctor in England and an American doctor in Germany to diagnose me. It also took a doctor from my local surgery that was working against the rules to give me any treatment. I hope you can do something with this: it's not everything but it's a start. If we help one person then some good will come of all this.

I have been asked what I want from all this? Well I want my country to love me as I love it. I want the NHS to give people the help they have paid for over the years. I want my family to grow up loving life and not fearing it.

Paul Bramble circa 2005

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