

## My children, my fight, my story.

An Ehlers-Danlos Syndrome family wrongly accused of child abuse; the mothers perspective..

My partner and I had twins via privately funded IVF due to my inability to conceive; my hormone levels were too poor for the NHS to provide fertility treatment. We felt our IVF success was a real miracle as we had conceived a boy and a girl; our whole family in one go. We used to call them the 'mini-meets' as our daughter had my colouring and our son had that of his father. When they were four months old my daughter (who was a failure to thrive baby with chronic reflux, sickness, poor feeding, breathing difficulties, multiple haemangioma and so on) stopped breathing at home and became unconscious. She and I were taken by air ambulance into hospital where they diagnosed a reflex anoxic seizure (faint) although later on it turns out that her acid reflux had likely sent acid up to her vocal cords and paralyzed them causing cessation of breathing (a laryngospasm) and then unconsciousness. She was discharged the next day. In hospital she had seemed hot to me but the nurse who took her temperature told me she was normal. That night she had a high temperature and I was watching the soft spot on the top of her head as one hospital medic had mentioned to another he thought her fontanelle was raised, the second one thought not. I was worried about my daughter as something didn't feel right despite the medic's assurances. Later that evening I called out the on call doctor who said she was fine. The next day I phoned NHS direct and spoke to her GP. The following day I took my baby to her GP, and later phoned her GP and finally the next morning, three days after her discharge, I decided to take her back to hospital. This was because although she was over her temperature and feeding better, I thought her fontanelle (soft spot on skull) was definitely raised. She was admitted and two days later, after her having had an MRI scan and a CT scan, we were told she had subdural bleeding and this was likely a case of shaken baby! Skeletal surveys followed for my daughter and my son, and MRI and CT scans for my son (they insisted we bring him in and he have these done although there was nothing whatsoever wrong with him - he was his normal happy self). Through these medical images, and the repeat skeletal surveys done two weeks later, my son was found to have a subdural bleed and rib fractures, my daughter additionally had a rib fracture and a forearm fracture. The hospital took what they referred to in reports to police and social services as 'a detailed family medical history' which consisted of 25 words on a piece of A4 paper, and some of these were errors. They then pronounced this was a case of shaken baby/non-accidental injury likely perpetrated by the parents and my children were forcibly kept in hospital for two weeks as 'a place of safety'. This is particularly ironic in hind sight as one of my son's subdural bleeds and likely three rib fractures, as well as my daughter's fractured wrist were caused in hospital while they were being 'kept safe'. I was only allowed to be with them if there was an agreed

supervising adult in the room with me. At the beginning of the two weeks, just post initial accusation, my partner was himself admitted to hospital with a flare up of his recurrent kidney stones – he makes them continuously. He was in a ward almost above us. I was coping with caring for my babies in a goldfish bowl environment being watched by medics all the time; I wasn't allowed to have the door or curtains closed even to undress myself for bed. It was beyond humiliating but I told myself they would find the real causes of my babies' conditions; they were doing lots of blood tests and so surely they had to find out what was wrong and eventually give appropriate treatment (as the babies weren't getting it while all the focus was on an incorrect NAI diagnosis). I remember expressing this anxiety to a number of medics and pointing out things that seemed odd to me about my children like their blue whites of eyes; deep blue in the corners of my daughter. I made specific mention of my son's flat back of head, the white patches in their mouths and my daughter's very see through skin; you could see all the veins on head face and head. I pointed out the way they lay on their backs with their legs out flat on the bed at 90 degrees (frog leg position) and how my daughter's breathing was like an engine chugging (the laryngomalacia stridor). However all these were brushed off as normal, no one wanted to listen to me. The NAI diagnosis had been made and was being adhered to.

As my partner and I were accused of causing non accidental injuries to our twins and so the police began an investigation for GBH with intent. The social services wanted to take the children from hospital into foster care. However, on advice from Parents Against Injustice (PAIN) we refused to sign a Section 20 (which was voluntarily handing over parental responsibility to social services) so they took us to court to get a judge to grant a care order. However on that day in court an arrangement was worked out where the children would go to live at my parent's house and my partner and I could move into the flat in the roof of my parent's house. (I think the social services only accepted this because they didn't have their paperwork ready to put in for their care order and the hospital were discharging the children). The plan was that children would be locked away from us at night in their bedroom wing and we weren't to have any unsupervised contact with them – my parents or another approved and CBR checked family member had to supervise us at all times. An agreement was drafted in court and we all signed it. Hideous as this was at least I would be able to continue to care for my babies – my daughter's long standing feeding difficulties meant that I had worked out the knack of feeding her and she didn't feed well for anyone else. I was relieved she would not suffer via our separation.

One particularly cruel measure the social services imposed on us that sticks in my mind was when I said we could go out with my sister and her children as she would drive my children in her car and I could drive her children in my car. The social worker said no I wasn't allowed to do that – I was clearly considered such a disturbed individual that I'd

stop the car, take my niece and nephew out of their car seats, shake them and then strap them back in and carry on while their mother was in the car behind!! In the end I traded my car in for an old seven-seater Citroen to avoid the humiliating experience of my sister and all the children going in her car and I alone in mine.

The police had attended meetings at the hospital during the babies' enforced stay. Two police officers from the child protection unit attended a discharge meeting the day before the babies were allowed out of hospital. I was unable to attend and my parents and my partner's father attended in our place. My father's request to Dictaphone the meeting was denied as the social worker said she would be taking minutes. At one point during the meeting the senior ranking police officer leaned over the table and 'roared' at my mother that 'this was the worst case of abuse he had seen in his sixteen years'. This wasn't recorded in the minutes. Nor, one imagines, could it be true as there was no child abuse here. A week or so later we were raided by the police. They arrived at my parent's house and at our home (now not lived in) and searched through all our possessions confiscating cameras, phones, computers, printed and hand written notes (they even took my partner's own poetry book!). They flicked through all our books, opened all the CD and DVD boxes and felt over the children's soft toys. There was a terrible sense of unreality about it; was like we were in some weird nightmarish film. We had never had contact with the police, had no police records, so this was a complete bolt out of the blue. The police arrived in marked police cars and vans displaying no consideration for my parents (let alone us); the neighbors were clearly fascinated by the raid. The police had clearly been greatly swayed by the opinion of the accusing hospital consultant; they had made up their minds we had abused our children right at the outset.

Despite the court approved voluntary agreement being in place, social services insisted on putting the children on the child protection register for social services to 'have a frame work within which to work'. I remember the initial meeting where it would ostensibly be decided whether to make my children subject to child protection register measures or not – although clearly it was already a foregone conclusion from the start. Before the meeting the 'impartial' chairwoman told my father and I that in her twenty years of experience injuries like these were always non-accidental. When I tried to point out that putting them on the register under the category physical harm wasn't right as they had not suffered physical harm, indeed this clearly wasn't proven as no court case had taken place, I was shouted down by the chairwoman. The subsequent child protection review meetings that I had to attend were some of the most humiliating and demeaning experiences of my life. Having to sit there listening to the 'professionals' repeat again and again 'likely non accidental injuries by parents' was just soul destroying. I was never listened to and my repeat protestations that we had not harmed our children were met with looks of disbelief.

This social services 'bullying' came to a head when I was due to give birth to my new baby son (apparently I could conceive after all!). Social services insisted I had an intervention worker/approved supervisor next to me in hospital at all times. The fact I was having my baby via elective caesarean and hence wouldn't be able to leave my bed until the day after the operation, that my legs would be numb and I would have a catheter in place and so physically couldn't leave my bed if even if I wanted to for hours after the operation, counted for nothing. One social worker told me I might be lying about my legs being numb and hence by implication saying I could get out of my bed and attack my new born baby! It was horrendous. They had a case meeting three days before I was going to have my baby, I felt hounded by them right up until the last minute and given no time to prepare myself mentally or experience any expectant mother happiness. On the morning I was leaving for hospital to have the caesarean a social worker turned up for an unannounced visit half an hour before I had to leave. I had no time to say good bye to my babies or my partner before my sister took me to hospital. When allowed out of hospital I returned to my parent's house and my new baby was slotted onto the current care arrangements – no unsupervised contact at any time, even for breast feeding.

Most unfortunately my baby son had an accidental low level fall at 2 ½ weeks old and bumped his head. My father and I took him to hospital to be checked over where he was observed for 6 hours and then discharged. Upon arrival at hospital we checked in at reception and my son was found on the hospital computer system so I assumed they had all the details of our situation, supervision etc. as I had only left there two and a half weeks ago after having him under stringent supervision arrangements. I made no special mention of the hellish NAI accusations as I thought they had it all on file like our GP does when he logs onto his computer. Indeed, a nurse who filled out the admission form didn't ask the usual social services involvement question so in hind sight I suppose my belief they already knew about our situation was compounded by this. The accident happened on a Sunday so first thing Monday morning (9am) I phoned social services to let them know, and the children's guardian. That day I also spoke to the midwife and the children's GP and let them all know of my son's accident. The following day we had an unexpected late afternoon visit from the social worker and her manager who had come straight from a Public Law Outline meeting with the hospital and the police where it had been decided to readmit my son for skeletal surveys/MRI/CT/retinal examination – the full NAI workup. They said there was a box on the admission form that been ticked as 'no child protection concerns' and so clearly we had lied to the hospital and were untrustworthy. I pointed out no such question had been asked but I was not believed. My father asked who would they believe the family or the 'professionals', they said the professionals. They also wanted to put an intervention worker in the house as they said my parents were no longer trusted as supervisors, despite already having done a reliable supervision roll for nine and a half months. They told us they were

putting in a care order application and then left. We were in the High Court by the end of that week. Luckily while in hospital with my baby during these further investigations for NAI, my dad told a doctor that we had not been asked the question on the form and I believe she instigated finding the nurse who had completed the form. The nurse admitted she hadn't asked the question and that she had ticked the box herself. Her written statement was presented to the High Court at the end of the week. However, this did not save me the horrendous time in between; a time of sheer terror and agony dreading that at any minute the police and social services would turn up at the door and try to take my children away. In hospital my baby son had eye clips put in his eyes for the retinal examination that bruised his tiny eyelids – again something that sticks in my memory; they hurt my baby.

Despite the nurse admitting she had filled out the form herself social services still went ahead with the care order application. I had to be on the witness stand in the High Court the following week for over two hours while the LA tried to make my son's accidental fall into something deliberate and sinister. Happily the High Court judge saw it was indeed an accident and rejected the care application. We returned home, traumatized, to our supervised lives – now with a new social worker.

This situation continued for 18 months while the care proceedings progressed. I fought for my family with the only resource I had – my brain. I read all medical records copied to me as part of the court proceedings. In mine I read a letter to my GP from a physiotherapist I had seen that mentioned my hypermobility and a Beighton score of 7/9. I researched this and discovered hypermobility can be due to a condition called Ehlers-Danlos Syndrome. Weirdly, many of the other things I suffer with seemed to match the list of EDS symptoms. I went to my GP who referred me to a rheumatologist; she diagnosed Ehlers-Danlos Syndrome. That wasn't good enough for the LA. They continued to state 'if she has Ehlers-Danlos Syndrome' for many months until at last the diagnosis was seconded via clinical examination by the international connective tissue expert Professor Pope. He also examined my partner who seemed to me to display connective tissue disorder characteristics too (or course the LA were even more skeptical about both of us having collagen disorders). We both had skin biopsy samples taken and under the microscope patches of collagen mis-packing were seen in both of us. I had been right all along; we both had versions of Ehlers-Danlos Syndrome. During this process I came across the ridiculous stand point that if a parent is researching and trying to find out what is wrong with her babies (as no one else is finding out) she must therefore be guilty of NAI and merely looking for a good excuse to cover her evil deeds. The concept she may be just a good mother valiantly fighting for her family and the health of her children appears alien to many LA employees I encountered.

Despite having a range of symptoms of Ehlers-Danlos Syndrome the LA/social services treated the diagnosis with extreme skepticism. Even the guardian misread the medical reports (or was misinformed) about the EDS in the family; at one point she announced at a child protection meeting that the children didn't have EDS! It is hard enough living with a genetic disorder, hard enough coming to terms with the fact you have passed it to your children and seeing the signs of it in them and very hard to know that they will have to suffer the same pain that you live with. To have the LA (and the hospital) try to deny your condition (and indeed ignore it in the children on the part of the hospital) is doubly hard to cope with. The LA and social services (and the hospital) were extremely inconsiderate of me and my partner. They seemed to have made up their minds we were child abusing deviants right at the outset and were loath to change their minds. We were treated as sub normal; the bottom of the muck heap. At one dark point they had me feeling like I wasn't decent enough to go out in public among everyday people. I remember driving through the local town and seeing mothers with push chairs and feeling despairing of ever be able to be like them again when I had every right to be; I had done nothing wrong, I had always done everything I could for my babies and put them first at all times. I was a really good mother – why was torture being inflicted upon me?

We have never received an apology from any of the 'professionals' or organizations involved in our wrongful accusation and subsequent 18 months of torment. We were punished before the court case ever took place, and when it did it was found we didn't deserve punishment at all. In the High Court we were exonerated, the judge found some of the children's injuries to have actually have been caused, and likely to have been caused, by hospital staff – injuries we had been blamed for causing deliberately- and yet there has never been so much as a sorry. My babies were deemed to have longstanding (possibly birth related or even prior to birth) chronic subdural bleeds that rebelled with minimal or no trauma; indeed the contour of my son's skull had changed over the site of his chronic subdural bleed it had been there so long - and it had developed membranes (this was missed by the hospital radiologist). It was recognized that a feature of Ehlers-Danlos Syndrome in my family was easy bruising (bleeding) and that there is no reason why capillaries in the skin should behave differently than capillaries in the brain. Ergo my babies had a potential inbuilt susceptibility to bleeding as their connective tissue was weaker than a normal baby. The fractures were also thought possibly partly attributable to EDS as in our EDS subtype there can be a decrease in bone density.

One of the hospital letters after the High Court Fact finding that I came across stated that there was not enough evidence to support the NAI allegations. In fact there was lots of evidence, it all pointed to there being a medical cause for our children's fractures and subdurals, evidence saying it was not abuse. Even after this the LA seemed loath

to let go. They wouldn't let the all-party agreed court order go through as proposed by our legal teams; they had to have pieces cut out. You'd think they could at least have let us have had that, we had suffered enough. This Local Authority, I gather, is one of the worst in the country for the number NAI care proceedings.

I have Ehlers-Danlos Syndrome Hypermobility Type (type III). I suffer with a range of symptoms; pain being the most debilitating on a daily basis. Pain in my hips, back, knees, legs and shoulders. I have chronic pain, recurrent pain and acute pain. I have mitral valve regurgitation, lytic spondylolisthesis (back), Raynaud's syndrome (vascular), clicking joints, osteoarthritis (I need a hip replacement and am only 40), easy bruising/bleeding, abnormal scarring, thin skin, hypermobility, bilateral hip dysplasia (deformed hip socket), bilateral coxa valgus (deformed top of femur), patella alta (knee cap deformity), restless legs, palpitations, blue sclera, breathlessness, stretch marks since a teenager and if I get cold I just can't warm up so something wrong with my internal thermostat! I also suffered with pubis dysfunction in my pregnancies and nose bleeds as well as badly swollen legs pre and post birth and local anesthetic doesn't always work on my skin. I have frequent loose stools/diarrhea (IBS I guess), chronic tiredness, and my blood pools in my legs if I stand up for long (I call it salami skin as my legs go red/purple with yellow/white blotches showing through all over – livedo reticularis it's called). Sometimes when I stand up I get dizzy (Postural orthostatic tachycardia syndrome (POTS )) and I have actually fainted a couple of times if I haven't been able to sit down. My jaw dislocates if I open my mouth wide and my right knee cap subluxes on extension and reflection (partially dislocates).

My partner's EDS Hypermobility Type/ Joint Hypermobility Syndrome presents in a similar fashion although he is slightly less hypermobile on the Beighton scoring system (although can turn his feet backwards due to abnormal hip rotation) and he has the complications of chronic kidney stone formation, vitamin B12 deficiency, vitamin D deficiency, possible Crohn's disease, plantar platelet tears, severe headaches due to dural dysplasia, back pain, a stoop, temporomandibular joint dislocation, chronic fatigue, loss of appetite, sleeplessness, skin rashes, stretch marks, severe recurrent mouth ulcers (12 at a time), asthma and 'acid' tears that sting his eyes. He also has chronic, recurrent pain and acute pain.

Our children, although all under three years old, have already been diagnosed/observed to suffer with the following: Ehlers-Danlos Syndrome, multiple haemangiomas, gastro esophageal reflux, laryngomalacia (floppy larynx), noisy breathing, Harrison's sulci (rib pulled in by diaphragm due to respiratory problems/weak bones), thin skin, petechiae when held by hospital staff for blood tests (hence easy bleeding/bruising), delayed gastric emptying, effortless vomiting, hypermobility, blue sclera, fractures from minimal trauma, fatigue, bilateral duplex kidneys, bilateral vesicoureteric reflux (weak bladder valves that let urine back up to kidneys), chronic birth related subdural bleeds, breath

holding episodes, laryngospasm, recurrent urinary tract infections, chest infections, eczema and asthma. I have now taken my children to Bristol Royal Children's Hospital and they are under the care of a paediatric rheumatologist there – I would not trust the local hospital with my children again unless in dire emergency.

Sadly I already know of two other families with Ehlers-Danlos Syndrome who have also been wrongly accused of causing non-accidental injuries to their children and it is merely a year since our court case. Clearly there is an urgent need for policy change and education of hospital staff. If I already know of two more EDS cases there must tens, if not hundreds of cases country wide; immeasurable pain being inflicted on innocent parents right now. The attitude of the LA to one of these other unhappy couples when both parents were found to have Ehlers-Danlos Syndrome was one of 'it's too much of a coincidence [with our case]'. They denied the EDS in this couple and insisted on maintaining NAI accusations. All I went through and they have learnt nothing. But then one hospital consultant is in the minutes of my baby son's PLO meeting (held between the professionals after his accident) as saying that Ehlers-Danlos Syndrome cannot remotely be cause or contribute to my babies' subdural bleeds or fractures and that she couldn't believe the family (us) have 'got this far on that'. Physicians educate themselves; your ignorance of EDS is destroying lives.

As a final thought I wonder how many babies being investigated for NAI are found to have wrist/arm fractures and rib fractures on the second skeletal survey of which there were no sign on the first skeletal survey. Fractures timed by the court appointed expert to overlap with the period the baby was in hospital/care. Having watched the handling of my children by hospital staff (where they were forcibly held down during skeletal surveys and manhandled during lumbar puncture and blood taking while they screamed hysterically) I would think that any EDS baby is liable to fracture at these sights, or indeed other sights. Attributing fractures to an abusive event that happened shortly before the baby was admitted to hospital with no sign of injury (no bruising, no pain, no soft tissue swelling - nothing) is logically ridiculous. Parents are being blamed for injuries inflicted by the hospital and if hospital staff handling can cause a fracture in these fragile babies then so could a parent albeit unwittingly. You can't blame a carer for causing a fracture in a baby if they didn't know their baby was more susceptible than a normal, healthy baby. Nor can you blame them for not knowing that their child had fractured if, like my babies, they displayed no pain nor showed any external sign of injury.