

MY JOURNEY

by Natalie Carter

Last week, I got onto a busy rush hour train from London heading north. There were no seats left, so I had to ask someone for theirs. Reluctantly, they surrendered their seat and asked why I needed it; I was told that I look perfectly healthy, my tiredness and pain not visible. We had two hours before we reached the first stop, so never wanting to bypass a moment to spread awareness, I removed the scarf covering my neck brace and proceeded to tell them my story. I would like to share that story with you.

My journey has been a difficult one, and one in which I have learnt a lot about myself both mentally and physically. My boundless amounts of positivity have always turned the frequent downs into ups. My ambitions have had to alter somewhat but my stubbornness has always shone through. I have learnt how important it is to have close family and friends for support but equally how difficult it is to explain how EDS affects me.

I had a very energetic childhood; I was a competitive swimmer, a gymnast and a long distance runner, but there was always something that held me back, always something 'not quite right'. I was diagnosed with bulimia at a young age and could not get anyone to understand that I was just sick after every meal and it was not something I was forcing or wanted to do, and not because I needed control or had any problems with family life. At the age of 10 I fell on my arm playing football and dislocated my elbow. From then on, every time I

dived in the pool it came out; I often put it back into place and finished the race. Eventually I had to stop gymnastics.

At 15 I had a tonsillectomy with many complications; my throat just would not heal and the blood vessels kept bursting. Still without any knowledge of EDS I had ligament reconstruction on my elbow at 16. I had a bad reaction to the anaesthetics and the pain relief I was given was completely ineffective, instead causing me to be sick and hallucinate for two weeks in hospital.

My elbow eventually healed and I got into Liverpool University to study architecture. I spent my first year like every other student - working hard and partying even harder. In my second year I started struggling: struggling to sit at the same drawing board as the year before, struggling to 'think' beyond the pain and the tiredness, struggling with the 'fatigue' of just getting up and getting myself dressed. Studying took all of my energy and I could no longer

go out in the evenings. I frequented my local doctors with a different problem every week.

My back pain, that I put down to working at a drawing board for too long, was getting worse. One of my close friends who massaged my back every day started to notice that my thoracic spine was curving and that my ribcage was no longer even. A referral to a specialist resulted in a MRI which showed a syrinx with syringomyelia - a cyst caused in the spinal cord when CSF fluid builds up due to a blockage. I was quickly given a brain scan that showed Chiari (a structural defect in the cerebellum of the brain. When the indented bony space at the lower rear of the skull is smaller than normal, the cerebellum and brainstem can be pushed downward. The resulting pressure on the cerebellum can block the flow of cerebrospinal fluid). Having a diagnosis was scary, but I finally thought I had some answers and was scheduled in for an operation a few months later.

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My symptoms deteriorated very quickly. I could no longer walk or talk properly, let alone concentrate, and the majority of this time is a blur. I had bad reactions to all of the medication I was given. I was 200 miles away from my family and frightened. My stubbornness meant that I tried to continue, pushing myself very hard to study. When my head was excruciating and I could no longer even get myself to the toilet, I was admitted to hospital through A&E. This was the first time in my life that I had to give up on something, which upset me more than the fact I was ill.

Once in hospital, I was back to not being believed that there was anything wrong with me, despite having a diagnosis. I had lost a lot of dignity at this point and I find writing about and remembering this time very difficult; it is not a situation I ever want to be in again. I was transferred to a specialist neurological centre and my operation was brought forward.

I had not coped well with anaesthetic in the past, but this time was worse and analgesics were not helping at all. Post-op, a lot of my neurological symptoms improved but my headaches were getting worse despite MRI scans showing the decompression surgery had worked. My goals shifted from wanting to achieve a degree and having a successful career to needing to be able to get out of hospital, shower and go to the toilet by myself and get rid of my indescribable headache. My family were very supportive and I learnt how close I had become to the friends I made over the previous year and a half at university - friends that I now know will be there for me for the rest of my life.

No one knew what to do with me; I spent most of the rest of the year in and out of the National Hospital for Neurology and Neurosurgery having tests and treatments for my headaches. Then it happened! A junior doctor walked into my room, saw me sitting in an odd awkward (but perfectly normal for me) position and said "I know what is wrong with you."

It was at this moment I heard Ehlers-Danlos syndrome mentioned for the first time. I didn't even know how to say it, let alone spell it. I was then promptly diagnosed with EDS and postural orthostatic tachycardia syndrome, (PoTS), and suddenly everything that had come before made sense; the bumps in my journey were starting to

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smooth out. Treating my PoTS significantly reduced my headaches and gave me back a sort of new 'normal' life and definitely an appreciation of it.

In the years that followed, I took every day as it came. I was still suffering background headaches, prolapses in my bowel and bladder were making things difficult and, having been inactive for quite a few months, many of my joints subluxed and dislocated frequently. I managed to teach myself the hardest lesson very quickly: that if others cannot understand an unseen disability it does not mean that it is not there or it is not difficult; it is their

ignorance to be blamed. I managed with the help of a local personal trainer to start regaining my strength.

I learnt that for me, stress is a considerable aggravator, so I tried my hardest to manage my time as best as I could and to be as organised as possible. Liaising with doctors and getting myself strong seemed like a full time job, but my focus shifted. I wanted to finish university. I continued at my own pace

and had many bumps along the way; I had to learn that I could no longer always be a perfectionist, as I did not have the time nor energy to do everything 'perfectly'. But I DID IT - I came out with a First Class Degree.

I then went on to do an Architectural History Masters at University College London with the hope of progressing on to do a PhD and becoming a researcher and lecturer. An accident to my wrist damaged my ligaments beyond healing without intervention so I had to have another operation, which slightly hindered my studies. Despite my best efforts to keep my joints strong and healthy, I increasingly suffered from dislocations and subluxations. I was having constant reactions to the things I was consuming, touching and breathing in, resulting in a diagnosis of histamine intolerance. With management and medication this has significantly improved. I now follow both a low FODMAP and low histamine diet.

My fatigue and 'brain fog' are the worst symptom; sometimes however much I want to sit down and concentrate I cannot, which provides massive problems when trying to study, research and write about complex material. I persevered and have become fascinated with the history of disability within the built environment, particularly in relation to unseen disabilities; I take advantage of my disability to provide a unique insight from a different perspective. I want to continue on to do a PhD but am unfortunately not well enough at the moment to put in the hours

and concentration required. It will always be my aspiration and will be realised one day, but for now has taken a back seat and remains as a hobby.

I am lucky to be able to work part-time doing architectural 3-D visualisations from home. I felt pretty isolated when I relocated to Yorkshire to live with my very supportive boyfriend, who is my rock - he has taken time to try and understand EDS and the way it affects me. He has helped me with practical solutions to the daily tasks I find difficult; things that most people can take for granted. We never dwell on problems and instead look positively towards solutions.

Last year, I started to volunteer as my local Area Co-ordinator for EDS UK. With this role I have found a purpose to help support others with similar daily struggles. Sometimes you just need to have a good chat. I have made some close friends locally through the group and together we always find a different way

to achieve or do something. At the moment we have made it our mission to try and raise awareness of EDS locally.

Unfortunately, the purpose of my visit to London was that over the last few months I have learnt that I also have instability in my neck (Atlantoaxial Instability - excessive movement between the C1 and C2 joints), which probably caused my chiari in the first place. This news and the symptoms I am experiencing are daunting, but once again its just another bump in the road to over come - just a slightly bigger one. I am waiting to see a specialist neurosurgeon in America to discuss the option of surgery.

I no longer focus on the things I cannot do or have not been able to do; I appreciate the patience, determination and strength that EDS has given me. I try not to take on too much and live life at a slower pace. I try to live, eat and exercise my joints healthily and am constantly on the search for new

achievable challenges. Four months ago we purchased a Pino Hase, a semi-recumbent tandem with an independent free-wheel. I relinquish the control of the steering, gears and brakes to my boyfriend. This has given me a new lease of life. We are once again able to go out and explore - I would never be able to walk some of the routes we have cycled! I can exercise outside again, watching the countryside go by with my back and neck supported by the seat and my neck brace. So if you ever see a couple cycling by on a rather odd-looking bike, it is probably us avoiding the life's bumps in the road and appreciating something I can do and enjoy.

The passenger on the train learnt something new: just because I look well, EDS and my linked conditions normally mean I am hurting inside. I do not see an obstruction in my path but instead small obstacles that need to be overcome in order to follow a similar route. ■

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