

Samantha's Story

The beginning of my journey

My journey started in 2012 aged 17. I was working on Saturdays as a shop assistant in a bedding shop often lifting heavy items. One Saturday I found myself struggling to lift a light duvet cover off a shelf; my arms just would not do it! After that little episode everything went back to normal, with no recurrence that day. I shrugged it off and carried on with my work. Weeks went by and then it happened again. As I was lifting a duvet off the shelf for a customer, I came over all flushed, my hearing went, and I was struggling to catch my breath. I lost my grip on the box, my hands felt alien to me and I had hand tremors. It scared me. Again, there was no recurrence of this distressing episode for the rest of the day.



In August of that year I was experiencing more symptoms. I was dizzy much of the time and suffering hot flushes, night sweats and debilitating migraines that would not go away. These symptoms began to worry me. My colleagues started asking if I was feeling alright as I hardly had any energy at work. In September I went to see my doctor who put it down to stress. No one seemed to believe that I was experiencing these symptoms. I started doubting myself. Was I imagining everything? Then the symptoms become less frequent.

During January 2013, I developed a cough which led to a chest infection and I took some time to recover from this. Over the next few weeks I started passing out and was sleeping more during the day. I become breathless and my heart felt like it was going to fly out of my chest. I went back to the GP and would not be fobbed off. I knew that something was not right. I was hoping that my symptoms would disappear but, if anything, they were getting worse. I had numerous blood tests, ECGs and was then referred to have a tilt-table test at my local hospital.

Everything got a lot worse in April 2013. The day before my tilt-table test I woke up on my bedroom floor feeling disorientated, I couldn't remember what had happened. The last I could remember was being downstairs watching TV. My brother called an ambulance as I was finding it hard to stay awake. I had chest pain, pain in my neck and was struggling to breathe. After a CT scan on my neck I was discharged but I was scared as I had no recollection of what had happened.

The next day I had my tilt-table test and halfway through I became flushed; I felt I was in an oven being roasted alive; I become dizzy and disorientated. Was I paralysed? My mind was telling me one thing but my body was refusing to do anything. After the tilt test I was referred to a cardiologist at my local hospital.

Diagnosis

At the end of May 2013 I was diagnosed with PoTS and the relief that washed over me was overwhelming . Someone had finally believed me and my symptoms. If I hadn't seen the cardiologist I would still be thinking that I was imagining everything. I was put on Fludrocortisone and medication for my migraines and joint pain and referred to London for further tests. If my cardiologist is reading this, I would like to say thank you for believing in me.

2014 – to date

In October 2014 I had two days of tests at the NHNN, which were not as bad as I imagined! I was diagnosed with PoTS and Joint Hypermobility and confirmation of Raynaud's. I was offered CBT (cognitive behaviour therapy) to help me better manage the condition. I am now only taking Fludrocortisone as I want to try to control PoTS with minimum medication. During 2014 I realised I needed emotional support and received counselling. I would stress that asking for help is not a sign of weakness, it is a sign that you are strong.

When I was diagnosed with Raynauds and PoTS I thought my life would stop. If you are newly diagnosed I suspect you may be feeling the same. For me PoTS has presented new opportunities and made me a stronger person. I may have lost friends and missed out on job opportunities but I now know that it was not my fault or my choice to have PoTS. You never know what is around the corner. Someone once told me "You need to learn to control PoTS otherwise it will control you for the rest of your life". I am learning my trigger points and how to overcome them. I am doing more exercise and core strength training to becoming physically stronger. I am learning to listen to what my body is telling me so that I do not overdo it. Each day I am finding new ways to control the condition so I can live my life again and be happy.

I am slowly rebuilding my life; I have a hobby that I can do on the days my PoTS is bad. I have created a blog detailing my journey with PoTS. I help run a patient support group in Poole for patients living with PoTS and Syncope. I have an online facebook forum so I can talk to other people around the UK who are living with PoTS and I am one assignment away from finishing an online nutrition course. I still have bad days and I still pass out most days but it has become my new 'normal'. These past few years have been tough but I am determined not to allow PoTS ruin my life. What people need to realise is that I am still the same person I was before my diagnosis, it is just that my body now functions differently.

Through PoTS I have met some great people, also struggling with the condition, who have become good friends. I thought I would be alone, but I am never alone! My new friends know firsthand what my life is like now and, when I am feeling down, they have a way to cheer me up and make me realise I am not dealing with this alone and neither are you. Everyone who has helped me through my diagnosis whether doctors, family or new friends,

has helped me become a stronger person and has enabled me to see my life in a new light, so I say “thank you for standing by me”.

Samantha House

Link to my blog [here](#)