

Standing up for MS



Emma Taylor

The heavens have just opened on a cold October afternoon, as I stand at the end of a cherry-picker's arm, being lifted onto the Fourth Plinth in Trafalgar Square. I'm about to take part in Anthony Gormley's One and Other project, where, over the course of 100 days, 2,400 participants occupy the plinth for one hour each. I'm here to represent people with multiple sclerosis, such as myself.

You might ask yourself why anybody would opt to stand for an hour in the cold and wet in the middle of London, let alone somebody with a condition that can affect balance. I did it because it was important.

I was diagnosed with MS in May 2007. I woke one February morning with numb feet. I thought it was due to having walked home in the snow a few days previously, but when the feeling didn't subside, I consulted my GP. A few weeks later I developed pins and needles in my hands. A similar thing had happened to me ten years before, but I didn't think to connect the two instances until later.

Then I started to lose my balance and co-ordination. I remember walking through my office one morning and bumping into something. I had no idea what was going on. The following week I was too ill to go to work. I wasn't sleeping because my legs kept twitching. I tried to write something but couldn't hold the pen. I went to the doctor who advised I rested until I could get an appointment with a neurologist. By the end of the week the doctor advised I get myself checked out at A&E. I was very frightened but I wanted to know what was wrong with me.

I spent a week in hospital, received a course of steroids and was sent home with an unconfirmed diagnosis of MS. I thought I was getting better but a couple of weeks later I started to get a visual disturbance in my left eye. This led to my balance and co-ordination getting bad again. I was unable to get out of the bath one morning so my family took me to A&E again. I was admitted to hospital for the

second time and this time, after a lumbar puncture and MRI scan, it was confirmed that I had relapsing remitting MS.

At first I was a little relieved. I finally knew what was causing all this. I knew I couldn't die from it but then the realisation came - I had this for life. There was no cure. I couldn't walk or go to the bathroom properly. I would spend my days in hospital trying to sleep hours away until visiting time. I was very upset

I was then assigned an MS nurse, who brought me information and leaflets from the MS Trust that helped me realise that I needed to start fighting this. I found that there were things I could do and medication out there. I started to spend my days doing the exercises that the physiotherapists had left me and eventually started to walk again with the aid of crutches. Beta interferon injections were prescribed and I left hospital after six weeks.

When I look back at this now, it feels like I was in hospital longer than that. I've got a lot better. I have had some glitches with my medication and have changed to Copaxone, which is injected every day. This was quite a shock but it does get easier with time. I wouldn't say it's as easy as brushing your teeth but you do get used to it.

I went back to work in October 2007, having been off for nearly six months. It was hard to adjust back into it but I was lucky enough to work for a very understanding employer. My hours were reduced at first but I've been back at work full time now for nearly two years. I get very tired sometimes but I

can work flexible hours, so I can leave early if I like. I started a routine of always having a coffee and a read of the paper in the afternoon after work as I found this helped my fatigue and helped me to collect my thoughts.

Reading about the Gormley project struck a chord with me due to the nature of standing for one hour. At one stage I couldn't stand at all. Now here I was, over two years later, with the ability to still stand, work and live independently. This encouraged me to apply.

34,520 people applied for 2,400 places. When I heard I had been successful, I couldn't believe it. To be honest, for the first couple of days I almost rejected my place. What was I going to do? Was I able to do this?

That's when I remembered being in hospital and the promise I made to myself. In the future, if I was able to do something, I would always give it a go. It's a cliché but life is short. MS struck me in my prime but I got better, although I live with what feels like an axe above my head. It is important now that I do everything I can to live my life to the full.

When I stopped using my crutches, people would comment how healthy I looked, even though I felt awful. Friends and family would say that I was too young to have MS. This inspired me to stand up on the plinth for MS, to alert people to the fact there is no 'typical' appearance. It's a silent disease and no one knows unless you've having a relapse or use a walking aid.



My idea was that MS is like wearing a shackle. You feel chained to the disease. If you're still able to walk, then fatigue means that it can limit what you can get done in a day. I decided to literally chain myself to a pole on the plinth.

On the day, the first thing I had to do was go through the healthy and safety measures. The organisers were quite surprised when I produced handcuffs and a chain from my bag! I had a sign that said, 'Help release the shackles of MS', which I thought would get the message across. I also wore a radio mic for the people at home on the internet. As I was being lifted to the plinth, I remember thinking how unique this experience was. I probably wouldn't have applied if I had been healthy. Sometimes it takes a scare to make you appreciate things.

When I got on the plinth I forgot about my nerves and I enjoyed the experience. The rain was no concern. I had proved something to myself while raising awareness of an important cause.

A gentleman came up to my partner whilst I was on the plinth and asked who I knew with MS. My partner told him that I was the one with MS and he seemed surprised but said how brave I was.

My family and friends were very supportive and my mother-in-law called me whilst on the plinth. She has been a source of support for me and visited me everyday when I was in hospital. My family and friends have something to do with how well I am now. I think being in a positive environment can make a big difference.

I would like to thank everybody at the MS Trust for their support, not just for the project but for the help and advice from their website. I hope that by being on the plinth I can inspire others to fundraise for MS, to help develop new treatments and hopefully, one day, find a cure.

Watch Emma's hour on the plinth at www.oneandother.co.uk/participants/Emma_T_1

Sarah Kerton occupied the plinth in September. Watch her hour at www.oneandother.co.uk/participants/Sardonic