

Young-onset Parkinson's: a patient's view

Matt Eagles began experiencing weakness in his legs as a young boy. Now, at 41, cutting-edge therapy and excellent support enable him to lead a full, active life.



I was an extremely active seven-year-old when my life began to change. I loved swimming and the sea, and I was busy pursuing my imminent career as Jacques Cousteau's apprentice. In fact, I loved life. Naturally, I had never heard of Parkinson's disease.

At first I didn't think there was anything unusual but my swimming instructor noticed that my legs were sinking, and I couldn't stand up for long during school assembly. Perhaps my most vivid memory of that time is being chastised by my mum for not being able to stand on one leg when she was cutting my toenails.

Tortuous tests

My parents took me to see our GP, who seemed at a loss to explain why a young child like me could be experiencing such strange symptoms. X-rays on my knees showed nothing amiss, while a host of other explanations, including a brain tumour, drew a blank. Fortunately, the GP had the foresight to refer me to Booth Hall, a specialist children's hospital in north Manchester. I remained under the care of Booth Hall until the age of 13. I recall spending weeks there having numerous tests, coming home at weekends but returning each Monday for more 'torture'.

Eventually, I was referred on to the Manchester Royal Infirmary. It was there that I was first given a parkinsonian medication – Sinemet 62.5mg. I was 10 years old.

Sinemet helped me during my school-days and most of the time I was able to participate in the sport and activities I wanted to, although I was always last to be picked, which is tough for a young boy. Although I look back to my school-days with tremendous fondness now, they were actually full of bullying and heartache. I guess one of the consolations of having young-onset PD, though, is that you develop incredibly strong



Matt abseils down Manchester Town Hall to raise money for Parkinson's

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arms and upper body. When I began to beat members of the rugby team at arm wrestling, I became more accepted. I hated being 'different'.

Panic attacks

I was on Sinemet for 11 years until, at the age of 21, I began suffering terrible panic attacks. Following a spell in hospital and a change of medication to Madopar, I pulled through. I also undertook some cognitive-behavioural therapy at that time, which helped me. Nineteen years later I continue to take Madopar. It still works for me but over the years I have had violent, disabling dyskinesias and unpredictable off-periods throughout each day.

Apomorphine injections helped somewhat, but made me sick and were not the most practical things to carry round and use in public. I tried a pump, which was more practical, but useless in

warm weather as the dressings peeled off with the slightest hint of sweat, causing the embedded needle to fall out. It was also a real drag to prepare every morning (I used to inject myself).

The worst thing was that I couldn't do any sport unless I took the needle out. I finally got fed up and removed the needle for the last time just before I put on my skydive suit to do a 3,000 metre tandem skydive to raise money for PD. The previous year I'd raised hundreds of pounds abseiling down Manchester Town Hall.

Since I was 15, I have been a patient at the world-renowned National Hospital for Neurology and Neurosurgery in London, under the care of leading movement disorders specialists, notably Professor David Marsden, who first acknowledged I had the pathology of young-onset Parkinson's when I was 19.

Deep-brain stimulation

In 2006, I underwent an operation to insert electrodes for deep brain stimulation (DBS). This has eased my symptoms, but is far from a cure. It is controlled by a unit fixed to my chest wall. I can alter the amount of electrical current depending on my symptoms, but fine-tuning must be done by my DBS nurse or consultant.

I am now 41 and have been working full time since 1990, but I have the support of my family and friends, which is essential, and the team at the National Hospital are a tremendous comfort to me. I'm also out and about reporting on local football, writing reports and taking photographs. It's crucial to have an active life and not dwell on things out of my control. A positive mind helps to keep the body healthy and deal with the tremendous physical and mental strains that young-onset PD can bring.

- **Matt Eagles lives in Macclesfield, Cheshire, UK. See his football reports and photography at www.maccweb.org.uk/news/cat_index_137.shtml**