

Me and my neurological illness:

**Dysembryoplastic neuroepithelial tumour/
A transformational “weird feeling”**

Gregory Scott

Affiliation: Department of Brain Sciences, Imperial College London

Correspondence: Dr Gregory Scott, Post-Doctoral, Post-CCT Research Fellow and Honorary Consultant Neurologist. Postal address: UK DRI Care Research & Technology Centre, 9th Floor, Sir Michael Uren Hub, Imperial College London, 86 Wood Lane, London. W12 0BZ. UK. Email: gregory.scott99@imperial.ac.uk. Telephone: +44 (0)7909 691484

I was seventeen when I had my first “weird feeling”. It was breacktime in a school music room. A friend had taught me Robbie Williams’s “Angels” on the piano. After practice and out-of-the-blue, my mode of consciousness was transported to another place. It was like a dial on my neurochemistry had been turned, shifting my perception of reality to a totally altered regime. It came with a profound and paradoxical sense of familiarity, what I’d later describe as “déjà vu, only magnified a thousand-fold”. The episode lasted about twenty seconds, ending as quickly as it had started. I was to have hundreds more.

The next “weird feeling” wouldn’t be for a month or so, but over the next two years the episodes grew in frequency. They became routine. It was perhaps for their initial rarity, and then their familiarity, that I didn’t seek medical attention until I had started university, studying computer science at Imperial College. By then, I reckoned I was having ten episodes a day. They became a personal puzzle to solve, each event providing more data – of such direct, subjective, quality – but all-the-while remaining fundamentally mysterious.

I relayed this history to my GP. She explained that she wasn’t sure about the episodes. She first referred me to a counsellor to explore how I was coping with university. This didn’t seem to unlock an answer. She next referred me to a psychiatrist. It felt like he was on to something when he asked, “do you know what I mean by déjà vu?”

It was while waiting for his referral to a neurologist that a diagnosis came. Sharing a room over Christmas with my family in London, they witnessed me have a nocturnal convulsive seizure. An in-patient brain scan provided the answer, in the form of a bright discrete blob in my right temporal lobe. It was Millennium Eve.

A brain tumour, the doctors explained – slow-growing and amenable to surgery – was the answer to my puzzle, and my “weird feelings” were epileptic seizures. Textbooks described my episodes as “depersonalisation” and “derealisation”, words that resonated but did not do justice to the profundity of the experience.

Events moved quickly. I met a neurologist, who started me on carbamazepine, which controlled the episodes. Then, on 10th March 2000 – a date etched on my brain – I had an awake craniotomy at Charing Cross Hospital.

The lead-up to the operation was the start of an intellectual awakening. I had hours of pre-operative neuropsychometry, which was fascinating, and I repeated it on my Mum in the café afterwards. I underwent a language functional MRI scan. (I am left-handed.) I learnt the reasons for everything happening to me. I recall the day my neurosurgeon told me I would need an awake craniotomy and he faxed over a description of the procedure: it struck me as simultaneously the most sophisticated and barbaric thing to do to someone.

I remember the mixture of fear and excitement the night before my operation, lying in bed with my fiducials attached. The next morning, I resolved with my family to say a joke in the middle of the surgery. I don't remember much of the operation beyond announcing to the theatre staff, "This is going to be a weight off my mind." Thereafter I have only vague recollections of counting aloud and naming items in a shopping catalogue held in my field-of-view. My head was screwed into a frame, but I remember the surgeon moving into view to reassure me it was going well. It emerged that no cortical stimulation disrupted what I was doing – I am left-dominant it seems – and I was put back to sleep.

A week later I was discharged, but not before I watched my own case presented, with a video of the surgery and complete excision of the pearl-like tumour. My only complaints were a headache and sore jaw. I did better on repeat neuropsychometry. I sat my first-year computer science exams six weeks post discharge.

The experience heralded a cascade of events that have shaped the course of my life since. In an era when good patient-focused websites were rare, I soon created a website for people in my situation. It opened my eyes to the importance of information as well as inspiration for patients. The website won the Times Student Awards, and I was given a summer job at the sponsors, Dell. But I was hooked on neurology, and by my second year I was already looking at how I could take up Medicine.

I got a First in my computing degree, but by then I had resolved to study Medicine. I enrolled on an Advanced Computing MSc at Imperial while, in evening classes, I studied the Chemistry A-level I needed for the MBBS programme. I graduated as a doctor in 2008. I pursued an integrated academic training path, with my neuroscience PhD and Clinical Lectureship both at Imperial.

It is hard not to see having that brain tumour as peak experience. It may sound odd, but I feel grateful for it, lucky. It did not take my medical training to learn that – on the spectrum of brain tumours you could choose – mine was the one to go for, what turned out to be a dysembryoplastic neuroepithelial tumour.

The experience gave me many lessons. To have had those "weird feelings" I think of as a gift, for they are the best evidence that our everyday perceived reality is a construction, created through a process of what the consciousness researcher Anil Seth calls a "controlled hallucination". This phrase resonates because I got to experience – daily – what happens when that control is lost, when the construction

momentarily goes off-the-rails. This is a profound and enabling lesson because it makes you re-consider your normal perceptions and thoughts as the constructions they are. Here, I suspect there are similarities with the psychologically transformative effects of the psychedelic experience. I miss the episodes, not because they were intrinsically pleasant, but somehow because of this meaning they carried.

I also received a very personal lesson on the neurobiology of consciousness: that a misbehaving growth in my temporal lobe, triggering aberrant neuronal activity, could cause in me the most profound subjective alteration. This experiment made me keenly aware of the relationship between brain and mind, and leaves me wanting to understand the puzzle further.

The experience introduced me to the wonders of neurology and inspired me towards a career in it. To be faced with an organ still so fundamentally mysterious. And for clinicians working in neurology and neurosurgery, I appreciated then, just as I do now, that for us to deal with this organ, that home to patients' speech, movements, thoughts, memories, hopes, and dreams – for that to be the currency of our practice is a privilege, and it calls for the greatest heights of compassion and communication, exemplified by the neurologist and neurosurgeon I was so lucky to have care for me.

The experience recalibrated what I valued, and still affects how I perceive life's challenges now, as if the threshold for what's really worth worrying about is much higher than I previously realised. My academic mentor says I am unflappable. I sometimes wonder whether the reason I changed was neurological (neurosurgical) or psychological, but I realised it doesn't make the slightest bit of difference. I'm all the better for it.

Key point

The experience of a neurological illness of our own can inform our practice, but it can also be the inspiration to start a career in neurology.

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