

Life after Neurosurgery

I've looked into the Abyss...

...And I have lived to tell the tale.

Patrick Williams

Patrick is currently training to be a Dentist. After being diagnosed with Trigeminal Neuralgia in early 2013, he became a member of TNA UK. He focuses his efforts on fundraising for the charity, as well as openly talking about the condition to raise awareness. He underwent Microvascular Decompression surgery in December of 2013 and has been in remission for over a year now. His aspiration is to become a General Dental Practitioner to be at the frontline of diagnosis to ensure no one suffers unnecessarily.

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Please note: An alias has been used to protect the identity of the author.

Trigeminal Neuralgia started as a tingle in my lip in early 2013, just after I turned 20. Never would I have thought that this tingle would turn into something that would be so wholly consuming; to the point where it seriously affected almost every aspect of my life, both physically and psychologically.

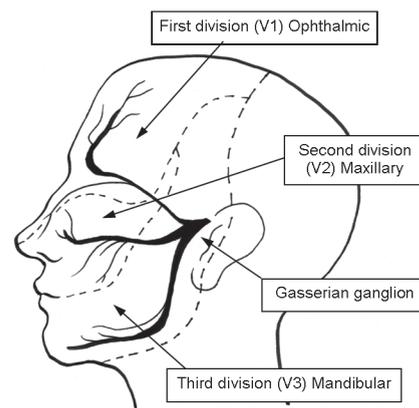
Two years later, I am in my final year of University, studying dentistry – a subject that I am incredibly passionate about. I'm often asked, 'Why dentistry?' It all stems back when I was a small child and pulled out my own wobbly teeth, followed by pulling out my little sister's wobbly teeth too! As you can see, I was a gory little monster!

Back on topic, initially the tingles were only felt when I washed my face. Now, when I say tingle, it was more a "sharpness". It wasn't exactly pain...but it wasn't pleasant. Imagine if you'd bitten into a lemon and the sharpness made you withdraw. It was kind of like that, but along my upper left lip. I must admit, as a dental student studying many rare conditions, I was armed with far too much knowledge which sometimes made me occasionally neurotic! I instantly said: "This is Trigeminal Neuralgia". I lived with other dental students and told them of my suspected self-diagnosis. They all reassured me it certainly wasn't. I went to a medical professional with my concern, who also reassured me it certainly wasn't. A week or so went by, oh, it certainly was Trigeminal Neuralgia.

The pain was something that should be restricted to the most horrific and dire nightmares. Permit me to paint the picture. Imagine a knife that has been plugged into the main's electricity and repeatedly stabbing you, ripping from the lip to the teeth and up to the lower part of the eye and base of the ear. A microsecond pause. Then repeat, and repeat, and repeat...This electrically charged stabbing pain was relentless, repeating all day, everyday.

I eventually coerced my GP to write me a referral letter to a Neurologist. After a month of agony, I was seen by a specialist who confirmed my diagnosis. The drug regimes began. My world, which had already been turned upside down, was plunged down into the darkest place I have ever ventured. My life narrowed to existing, not living. Taking each second as it came.

I tried several drugs...and then combinations of drugs...and then drugs to control the side effects of the original drugs. Carbamazepine, oxcarbazepine, lamotrigine, gabapentin, pregabalin – I tried them all: a connoisseur of anticonvulsants. But all with little avail. The pain broke through the medical barrier in regular bursts, hundreds of times a day. 'Tic Douloureux' – painful tics in French – is an



accurate name for this condition. The flinching was so bad I was once asked to leave a restaurant because the proprietor was worried about accidental damage and me knocking something over. I felt I was at battle with my body. The simple act of shaving turned into a task filled with dread. Even trying to eat soup through a straw became a fearful exercise. The drugs turned me into a zombie. I found it exhausting just keeping my eyes open for a few seconds, so much so it required another eight hours sleep. To stand at the Abyss, the darkest place you could ever be, look over the edge and truly wonder if it'd be better there than here. It is no coincidence that Trigeminal Neuralgia coined the term Suicide Disease.

On December 16th, 2013, Mr Ian Sabin, consultant neurosurgeon, performed a Microvascular Decompression (MVD) and returned me to a pain-free life. I was overjoyed. I came off my drugs slowly. There were a few tingles and a couple of sharp bouts. This terrified me. But Mr Sabin reassured me this was quite normal and would settle down. And it did. I am eternally grateful for what Mr Sabin did for me.

So where does Post Traumatic Stress Disorder fit into all of this? It's a condition that affects war veterans and those who have experienced the most terrible of things that are violently traumatic, right? So why was I there reliving hell? I would sit at my desk, ready to revise, so grateful for being alive and pain-free. But intrusive thoughts and images would invade my mind. What if it comes back? I suffered constant flashbacks of the worst situations I'd previously been in...like sobbing uncontrollably in public and getting odd looks or angry stares. Several times a week I would awake in a cold sweat imagining I'd felt pain in my face. I'd rub my lip viciously to confirm there was no pain...or was there? No, no, there was none, was there? Did I feel something just then? Had that been a tingle? If I drank

cold water and dental sensitivity occurred, I would be inwardly petrified. I couldn't focus. I developed 'safety behaviours' like double tapping wood or my head in order to not 'tempt fate'. The anxiety and incessant head tapping often brought on headaches, and I'd get sudden panic attacks which would stop me in my tracks, whether I was walking in the street or in clinic, making me feel as though I was about to be violently unwell.

I felt ashamed. There were people who had gone through far worse than me – wars and assaults. And there I was, a twenty-year-old with absolutely nothing wrong with him, having these intrusive thoughts just because of a condition that most people had never heard of. I was a freak.

I went back to my GP who rolled his eyes, but did agree to refer me to a therapist at Compass Wellbeing in London. After nearly a year of EMDR (Eye Movement Desensitisation and Reprocessing therapy) and CBT (Cognitive Behaviour Therapy) I came to understand it was irrational to feel this way. I was dealing with an uncontrollable stress response due to previous constant pain, fear, anxiety over when the next attack would be, or if I would stay pain-free now I was finally in remission. All these irrational thought processes had stacked up and never been dealt with. My brain had put these old memories and anxieties into boxes with open lids, so they spilled out whenever and wherever.

PTSD really impacted on my life. I wasn't able to form meaningful relationships with the people around me as I was so scared that no one would understand me, or that I'd be labelled as "some crazy" who considered himself a survivor of an imaginary disease! It wasn't only my social life that was affected. I was anxious all the time. I jumped at loud noises or unexpected movements. I had panic attacks at the most inopportune of times.

I believe Trigeminal Neuralgia really does impact on you mentally as well as physically. There needs to be a pathway for patients to get the emotional and mental support truly required. Not everyone will need or want it, but it should nonetheless be offered. It takes a lot of courage to ask for help, even more so to ask for mental health assistance because there is a stigma attached to mental health. Sometimes, all we need is for someone to acknowledge that what we're feeling is normal. That we're not freaks. We're Survivors.

So here I am, now aged twenty-two and life is sweet: Nearly two years in remission from Trigeminal Neuralgia; recovered from PTSD; a Trustee to a wonderful charity; a great social life; in my final year of dentistry and, possibly most important of all, now able to talk and write about my experience with Trigeminal Neuralgia and Post Traumatic Stress Disorder. Some days I may wobble, but I am not alone. I'm stronger now thanks to the cards fate dealt me and am proud of the path I walked.