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Getting On My Nerves: A memoir

(For the *Journal of Critical Psychology, Counselling and Psychotherapy*)

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Pubic/private?

I suffer from trigeminal neuralgia (TN) and have done so for several decades. The condition is intermittent but tends to get worse with age. Sometimes I'll get a fortnight or so of chronic attacks. Other times, just a few twinges. But when a full attack kicks in, the pain is utterly unbearable. The term 'suicide disease' has been bandied about (Sarmah, 2008) and I have a good idea why.

There's a railway track handy, just at the bottom of my road.

The affected area is the trigeminal nerve which has its root in the brain just above and behind the ear. In my case, the problem is on the left side. Three nerves, the ophthalmic division (V1), the maxillary division (V2) and the mandibular division (V3) stem from the root. V1 provides sensation to the forehead and eye; V2 to the cheek; V3 to the jaw. So, during an attack, the whole of one side of the face experiences unbearable pain which can last for hours. If you have ever had a bad toothache, imagine it multiplied by ten and affecting a quarter of your head.

That's about the half of it.

In fact, when I first started getting facial pains (in my early 30s) I assumed it was a problem with an impacted wisdom tooth and went to see my dentist who, naturally enough, could find nothing wrong. My GP at the time was equally baffled. I took pain killers on bad days and tried to, as they say, push through.

Not long after my 50th birthday, the condition was getting so intense and so frequent that I was using a codeine-based pain killer in quite large doses on a daily basis. My work as an academic and university administrator was becoming all but impossible. I was missing days of work, finding that codeine-induced sleep – if at all possible – was the only way out.

When at work, I was often drowsy and taken by some to be intoxicated; which, in a way, I was. The culmination came at an awards ceremony when, after a glass of wine, I was deemed to have been drunk on duty and faced a misconduct charge. Universities get more and more like the armed forces by the day. By an incredible coincidence, at the ensuing ‘counselling’ sessions – conducted by an HR manager in extremely adversarial style – it turned out that the appointed mediator (from an outside HR company) was also a TN sufferer and knew exactly what was going on. The charges were dropped and I was ordered back to barracks.

But the strain and stress of the process were too much to bear on top of the bouts of TN. A colleague in the Law School quietly told me a certain senior administrator had a black list and I was on it. There was a fair chance that said administrator’s incompetence would become obvious at some point; so I was determined to outlast him – stress, strain, pain and drugs or no. As soon as he was packed off elsewhere, I took early retirement. I was 56 and possibly the youngest Emeritus Professor in Australia. The pension would pay \$500 a week and still does. I sold expensive in Fremantle and bought cheap in a semi-rural area south-east of Perth. It was just doable with a bit of help from the income from continuing with my Honours and PhD students.¹

Not long after retirement, I went to see a new GP at a local practice. He listened carefully to my pain experiences and decided that the best course of treatment

¹ Though, as I write, Murdoch University has found a regulation which prevents such payments to honorary appointees. I am now expected to supervise pro bono.

was a regular dose of Tegretol (carbamazepine), a drug more often associated with the treatment of epilepsy. It works by effectively damping down the whole of the CNS in order to control just one small part of it; the proverbial sledgehammer and nut situation. The Tegretol works quite well once the right dose is found and now I can self-titrate depending on the frequency and intensity of episodes. The downside is that it's a bastard in terms of a continual slight drowsiness. The upside is that I can now sleep at will. My new party trick.

But I did not want to be on the thing for the rest of what was left of my life. So early last year (2013) I had another long discussion with my GP who referred me to a well-established Perth-based pain specialist. Light at the end of the tunnel perhaps? Not quite. When I called for an appointment, the receptionist's first question was about my level of private health insurance. 'Nil', quoth I. In that case, I was informed, I could not be given an appointment.

I tried to explain my political stance. In 1997 the Howard government had introduced a pincer move to get people out of the public and into the private health system. If you didn't take out private cover, you paid an extra 1-1.5% per annum Medicare levy. At the time, I had an associate professor's salary and 1.5% of it (thereby doubling the normal levy) would easily have bought me very good private cover. But I refused the pincer move and supported the public health system instead. The conservatives are good but. They know which way most Australians will go when given a choice between private interest and public good.

The receptionist heard about four words of this and hung up. I called back a day later and spoke to another receptionist, saying this time that I was prepared to pay the consultation fee up front and out of my own pocket. Still no good, I was told. The doctor will only see privately-covered patients. No reason, no nothing.²

² I have since been told by a practitioner on the 'inside' that pain specialists have this policy to prevent illicit drug users from getting prescription opioids. In short: to keep out the riff-raff.

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Wittgenstein and the pigeons

And so ... back to the GP (for another \$70 appointment) with my sorry tale. So I got a second referral, this time to the public pain management system. I'd assumed this would be to a clinical practitioner in a public hospital, the public equivalent of the private guy. But when the appointment letter turned up, it was for two days of self-training sessions. By now we were into November 2013, about eight months since starting on this journey, and the last thing I needed was self-training! But that's the rules of the public system. You have to go through the sessions before you can see a public pain management clinician.

There's a slight irony here. When I first retired, I had a bit of time on my hands. So I worked in volunteer medical transport, driving frail, infirm and hard-up folks to and from medical appointments. I got to know one 'client' quite well and part of his 'treatment' was the afore-mentioned sessions; though a longer stint – several weeks of two half-day sessions – was 'required' in his case. Poor bugger! Each day, he'd come out looking and feeling worse than when he went in. I'd hang around in a local café all morning or afternoon then go to pick him up for the trip back home.

Every day, much the same conversation. 'How did it go today? Any better?' 'Nope, they're still telling me *I don't have any pain. It's my brain that has it. Bloody useless as a one-legged man at an arse-kicking party*'.

So I was, to say the least, sceptical and my scepticism was reinforced pretty much from the word 'go'. Mostly the sessions were run by clinical psychologists who pushed a constant line of (and here I quote from my notes):

- It's not all in your head/mind. It's real.
- It's real because of how the pain receptors in your brain work.
- Your brain *sees* ...; your brain *sees* the pain as a threat and so
- Our brain *tells* us ...; the signals from, say, your leg, *tell* the brain
- The brain *pays attention*; your brain *is noticing*

Need I go on? On the second day, I took along Bennett and Hacker's *Philosophical Foundations of Neuroscience* (2003), a book large enough to be conspicuous – deliberately so – and used its fabulously detailed contents page to find counter-positions to the session lecturers. Particularly useful was the chapter on the Mereological Fallacy (pp.68-107), the attribution of psychological attributes to the brain. Bennett and Hacker's attack is on the view that: 'the brain *experiences, believes things, interprets clues on the basis of information* made available to it, and *makes guesses*' (p.68), among the many other 'brain + psych-predicate' formulations they find at every turn in contemporary neuroscience. Their position against this rather strange type of formulation comes from Wittgenstein (1953, §281):

Only of a human being and what resembles (behaves like) a human being can one say: it has sensations; it sees, is blind; hears, is deaf; is conscious or unconscious.

Ah the consolations of philosophy!

Not that the lecturers got to hear any of this. We, their audience, got to say very little; albeit that their organisation proudly describes itself as 'a patient-initiated clinical service'. When I got my half-minute to speak, all I could manage was: 'You say it's the brain that does these things? Well the cause of my pain *is* in my brain. The trigeminal nerve has its roots there and I have a lesion to prove it. [Did I?] But my brain isn't doing any *seeing* or *telling* or *paying attention* or anything of the sort, especially not *feeling*. The brain famously doesn't feel much. *I* feel the

pain and it's bloody awful ...'. Here I was smartly cut off. Pigeons don't appreciate the sound of cats.

I'm fairly sure their Mereological Fallacy failed to convince the cancer patients, the ones with chronic back pain, or the ones with limbs all-but hanging off. And it certainly didn't convince a lifelong devotee of Wittgenstein and Ryle armed with Bennett and Hacker.

Apart from the brain talk, a fair bit of time was taken up with lectures about, and pen-and-paper planning for, 'pacing'. Chronic pain sufferers were advised, for example, to try walking for 6, 8 or 10 minutes daily, building up to three times a day. Other suggested activities suitable for 'pacing' were carrying, sitting and driving. All of this seemed very odd to me. When I don't have pain, a 10 kilometre bush walk is easily doable. When I do have pain, it's a problem getting as far as the bed. I was starting to wonder why a triage system was not used for these sessions so as to sort out the *types* of pain people experienced before making them sit through a one-size-fits-all program. Almost nothing that was said would have been of use to any TN sufferer. In the private system, we go straight to a clinician. What makes public-system TN sufferers so different?

Still, the final lecture *was* given by an actual pain clinician, the kind that deals with actual somatic problems and knows about medication and surgery.

Although he rushed through it a bit and didn't mention TN, I knew he was the kind I needed to see. If they'd allow me. I did manage to bail him up at the end; though, from personal experience of lecture-repetition-overdose, I could tell he was anxious to get out of there. Yet he did tell me a few interesting things. For example, I should not take more than 90mg of opiate-based pain killers a day. (As if!) That opioids can reduce testosterone. (No comment.) And that Tegretol is only good for problems 'above the neck'. (Yep, that's me! V1, V2 and V3 are definitely above the neck). He also ran through some of the alternatives. Neurotin had been mentioned quite a few times that day as a pain treatment. A number of the

attendees had found it useful. But his verdict was: ‘No good above the neck. Absolutely useless’. I was starting to tick things off my list.

I drove home and thought about all this. But not for long. There was very little *to* think about. The only question was: what could be the next course of action (if that’s the right word) in the public health system? Which is how we come to the next chapter in this saga.

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I am clinically certified as intelligent

At least I had completed the degradation ceremony of the pain sessions, so I was duly qualified to get follow-up treatment; a one-to-one session with a psychologist, a physiotherapist, an occupational therapist, a dietician or, as I obviously preferred, a pain management specialist. After all, this had been the whole point of my GP’s initial referral. This meant making a call back to the pain unit that ran the sessions. Only they could certify that I had actually completed them and make a referral. The call was not without difficulty though. The (I assume, clinically unqualified) receptionist tried at every turn to prevent me getting an appointment with the type of clinician I needed. She suggested, instead, that she should send me a pamphlet about TN. That didn’t wash. I told her more about the condition than she could tell me. And anyway they were out of pamphlets at the time. So she said a psychologist might be a better way to go. Didn’t wash again – you can imagine my response to that one. I was bloody determined. Then, and this must surely be an ethical breach, she suggested I take Neurotin. I ducked this one by telling her what I was currently on, its proven use in controlling TN, and what the *qualified* specialist at the sessions had told me about the uselessness of Neurotin for that purpose. She was out of diversionary options and I got my appointment. Not without a fight. Seems the medieval romances are right: you have to get past the dragon to get to the gold.

So in January 2014, almost a year after that initial referral, I got to see a clinical pain management specialist. I fronted up at a public hospital, waited about an hour, and finally came face to face with a pleasant enough chap of (I guessed) some 27 summers. We started talking about possible treatments and our young man seemed to think that continuing with Tegretol was the best option – supplemented by one or more of: Baclofen, Pregalbin, Amitriptylline, Clonazepam, Oxycodone, and Lignocaine patches. In short: keep taking the pills. I pointed out that the whole point of the initial exercise (the ‘management plan’) with my GP was to obviate the Tegretol, not to add more pharmaceuticals to it. And could we now discuss ‘interventional treatments’ ... please? I had started to learn that begging was a better tactic than confrontation.

The interventions I’d heard about – largely from fellow sufferers’ web sites – were microvascular decompression (MVD), radio frequency (RF) treatments and gamma knife (GK) procedures. But there were also a few others I couldn’t name at the time. Here, the young doctor was less at ease. He seemed not to know much about the details of such treatments and their comparative advantages and disadvantages. Slightly out of his depth on such matters, but at least knowing they weren’t undertaken at his hospital, he gave me a referral to a neurosurgeon at another one.

When I got a copy of his report to my GP – a letter which I shall have framed and hung in my home library – I was interested to find the following observation:

Alex [sic] is intelligent and [has?] obsessive compulsive traits which includes [sic] understanding [of?] and treatments for the trigeminal neuralgia.

A very insightful comment from a 20-something with no formal qualifications to assess intelligence or ‘obsessive compulsive traits’. I wondered about his own

intelligence and whether or not, were he a TN sufferer, he would be obsessive or even compulsive about finding a suitable treatment. At least my GP had a good laugh at this one.

What happened next surprised me. I was given an appointment with the neurosurgeon for only a few weeks later, in mid-February 2014. After a fairly arduous journey on public transport (parking is impossible at most public hospitals in this part of the world), I arrived on time and, again to my surprise, was ushered in to see the neurosurgeon within a few minutes. I recognised him because, on my way up to the waiting room via the staircase – the lift was out of order, of course – I'd overheard him and one of his students discussing nothing other than TN itself.

Here at last was the encounter I'd set out for. And it did not prove at all fruitless. All the available options and their likelihood of success were discussed. It was a long consultation, perhaps in order to give the observing student time to take notes. Which also gave me a chance to take notes. Given the options available in the WA public health system – i.e., without travelling interstate or overseas – it turned out that the most likely suitable treatments would be either (a) Percutaneous Stereotactic Radiofrequency Rhizotomy (PSR), a heated needle into the trigeminal ganglion via the cheek to destroy selected nerve fibres or (b) the aforementioned MVD in which, via a small craniotomy, the stem of the trigeminal nerve is separated from a nearby artery with a teflon sponge. This on the assumption that the cause of the neuralgia is interference between the artery and the nerve. If I was suitable for the second option, the neurosurgeon suggested this as the best course of action – with the downside that, in 0.2% cases, brain damage or death could result. Was I suitable and, if so, would it be worth the risk? The first question could only be settled by undergoing an MRI test.

The neurosurgeon then made what I thought was an excellent suggestion. I could get the MRI done quickly via a private provider or I could wait to have it done in

his hospital as a public patient. To my surprise, he suggested the latter. This would have the advantages, he said, of both giving me time to consider brain surgery and also accessing the superior MRI machine (best in WA he said) just around the corner. So, for the first time, I was happy with the time lag. I felt I was getting much closer to my goal: no TN and so no drugs. Not to mention an end to the degradations of the public health system.

The MRI was set for early in May; about a couple of months later. Plenty of time to ponder surgery and to discuss the situation with my loved ones. I'd had an MRI before for a bout of pancreatitis and it seemed straightforward. But that was a fairly brief scan and I was given a lot of pain killers for the problem. So I felt almost nothing. This time was different. When fully lucid and going through an extensive (one hour) session of MRI, let no one tell you it's non-invasive. One invasion is the fluid injection required to bring out the required brain images. They warn you of the side-effects in advance and need a signed agreement before administering it. The other is the acute discomfort. This was partly my own fault. I had failed to tell the operators about a congenital neck problem so that the posture they put me in and required me to hold for an hour was excruciating. The pain ran down from my neck and through both arms until they were vibrating with pain. In between the various passes of the test, the operators kept insisting that I keep still. I could not. Several of the parts of the test had to be repeated. By this time, the elevator music coming through the headphones had stopped and the hideous noises of the machine were fully audible. (I'd brought along a CD of the Milk Carton Kids – highly recommended as a calmativ – but they couldn't use that.) I can't describe these noises. I want to forget them. I have forgotten them. All I can say is: it was good to get out of there.

The follow up with the neurosurgeon was a week later. The appointment was set for 2:50pm. A whole *room full* of people's appointments were set for 2:50pm. I have no idea why they do this. The medico has a list of 30 people to see that afternoon and they all get the same appointment time. So I was waiting until 5:30

until I could go in. Such a contrast with my first experience there. At least I had a good novel to read.

Another contrast was the length of this consultation. After the long wait, it lasted all of five minutes. Upshot: the MRI showed no neuro-vascular compression. MVD was out of the question. My TN must have another cause. They could try PSR but they didn't like to do it because of possible damage of the ophthalmic nerve (V1). In that case, all sensation to the left eye would be lost and if, say, a bit of grit got in there, I would no longer be able to feel it and the eye could be seriously damaged. The neurosurgeon was duly reluctant. And so was I.

So we come the end of this chapter, but not of the story. Not yet. I'm set to see a neurologist at yet another public hospital in September to see what he thinks. Maybe he can find some other cause of the TN. Maybe not. Maybe it's TN, Tegretol, codeine and the indignity of public health for the rest of my days.

* * * * *

Coda, 19th September 2014

Yesterday I finally met the neurologist. It was a long consultation in a public hospital – almost an hour and a half in all. He was immensely thorough, taking me through the history of my condition, descriptions of the pain and the details of my attempts to get to a solution, pretty much as narrated above. Then he gave me a complete neurological examination and only then consulted the MRI. Pause. 'One thing is certain ... you don't have trigeminal neuralgia'. None of my symptoms matched the condition in any way. He'd seen too many cases of genuine TN to know that. What I do have is one of the manifold varieties of migraine. I also learned that the popular idea that migraine is a purely cranial kind of pain is misleading. It can affect any part of the head, almost always unilaterally.

How strange to find that the diagnosis I had taken for granted and had been living with for six years was mistaken. Seems Tegretol is also used to control migraines – which explains why it's been working. But now that I finally have an idea what's going on, there are other possible treatments. And that's the next stage of exploration.

I must apologise to the reader if I have wasted some of their time. But I think not. I have written in good faith about my experiences in the public health system and the difficulties of getting to the upper echelons. But it's been almost worth the struggle to finally arrive at an aetiology that makes sense. It has also been philosophically instructive to be able to see my brain in 3D; as a kind of movie even. I did not see any memories, thoughts or beliefs.

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