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One Eye Open

You have twelve cranial nerves. You probably didn't know that. Why should you? Unless you're a doctor—or someone like me—you probably also haven't given much thought to the fact that the seventh of these travels through a narrow canal of bone beneath the ear to the nerves of the face. That if the nerve gets inflamed and swells, signals stop going through, like water through the hose you stepped on one summer. That it just so happens those signals allow you to do things you take for granted every day: whistle a tune while you wash the dishes, blow up balloons for your son's sixth birthday party, smile broadly when your young daughter gives you a card she's made from construction paper and covered with heart stickers. If you're someone like me, who can't do these things, cranial nerves—how many and what they do—take on a new interest. What I would give to whistle. What I'd give for my face to look the way it used to. Not like Brad Pitt's or anything. Just normal. Like yours.

Like so many stories, this one began with a clue too subtle for notice: a headache on a Wednesday in late April 2012. To that point, it had been a normal year. We'd planted pumpkins behind our home at the time, in the village of Ashhurst outside Palmerston North. I'd just published my second book of poetry, *A History of Glass*, and had arranged some readings in the US for May. I spent a good number of hours from Wednesday to Friday that week on the phone with airlines, trying to find a way to get my family to the US on air points. The process was frustrating and stressful. As I'm prone to stress headaches, I didn't pay this one particular mind. I just popped some paracetamol. I did notice the headache didn't respond; that the pain focused, unusually, on the right side of my head; that it seemed to be getting worse. I took a bite of my sandwich on the Thursday and it tasted terrible: I'd lost taste on the right side of my tongue. By Friday, the headache had migrated clearly to my right ear. I assumed I had an ear infection. The doctor's schedule was full, so

I resolved to see how it felt in the morning and to go to urgent care if it hadn't improved. I went to bed Friday night with a blazing earache. Saturday morning I woke up with half a face.

Maybe you wonder why I'm telling you this. For sympathy? Hardly. Look at the news. Refugees. Kids separated from parents. Countries going under the sea. If you have anything left in your emotional transaction account, this is hardly the place to spend it. And still, oddly, I go on talking.

Maybe, like me, you've misread the clue that had finally announced itself as one. Like many people who wake up unable to smile and with trouble closing one eye, I assumed I was having a stroke. My wife put me in the car, piled in the kids and took me to A&E (she had her doubts about a stroke, as I was offering helpful suggestions on her driving). I sat in the waiting room impatiently. I kept asking the nurse behind the window for aspirin. If I'm having a stroke, I said, shouldn't I be getting some aspirin? Why won't anyone give me some goddamn aspirin? When I finally saw the doctor, he explained that they first need a brain scan—an aspirin would make a potential bleed in the brain a lot worse. So much for knowing everything. A CT scan operator had to be called in from home to get a picture of my brain. Did I have a stroke or not? I asked when the doctor finally appeared with the results. 'Nothing that exciting,' he said. He handed me an information sheet on Bell's Palsy.

From the outside, if you knew me then, it looked simply as if my face had stopped working. It was a bit more complicated from the inside. Two days later I couldn't close my right eye at all, so I had to frequently apply ointment and drops, and use tape the eye to keep it shut at night so it didn't dry out. The facial paralysis was accompanied by headaches, earaches, dizziness, hyperacusis (everything seemed unpleasantly loud), and—for a frightening couple of days—neuralgia, a nerve pain that is agonising and debilitating: little zaps of lightning through my neck and chest so that all I could do was sit in bed and try not to move.

Though I was desperate for information, it was hard to read the computer for any length of time. My cursory searching online indicated that 85 per cent of Bell's Palsy patients make significant recovery within three weeks; 71 per cent eventually recover full function. To give a sense of how clearly I was thinking, I said we should go ahead and host a planned dinner party the next weekend

with several other couples. My wife took a firm hand, persuading me that this was absurd. Still, I clung to the information that a substantial recovery was possible in under three weeks.

Before my face collapsed, I had succeeded in getting plane tickets to the US. My first reading, in Baltimore, was almost exactly three weeks away. My wife stepped in again and said we should consider cancelling our trip, but this time I demurred. The timing was perfect. I should be in pretty good shape by then to read some poems to a crowd. As they say on the beer ads: *Yeah, right.*

This has nothing to do with you, right? Yet you probably know someone who's had Bell's Palsy, and I hate to say it but the odds you'll get it are shorter than you think. An old friend in the US who saw me at my worst—we hadn't been in contact for a long time—waved her hand without concern: *Yeah*, she said, *I had that.* The incidence of Bell's Palsy, depending on where you get your information, is between 11 and 40 per 100,000 people each year. To look at it another way, an annual rate of 20 people per 100,000—one cited rate in the literature—means that one out of 60 people will get it over a lifetime.

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Bell's Palsy is a diagnosis of exclusion. Facial palsy has been linked as a symptom to, among other things, sarcoidosis, Lyme disease, diabetes, brain tumours and multiple sclerosis. Once these causes are reasonably ruled out, the problem is attributed to Bell's Palsy. So why, then, does the facial palsy occur? You have to keep asking that question to get to the central ignorance around this ailment. It happens because the seventh cranial nerve becomes inflamed, blocking signals. Why does the nerve become inflamed? At various times the blame has been laid, according to an article in the *Western Journal of Medicine*, on 'viral infection, vascular ischemia, autoimmune inflammatory disorders, and heredity'. The viral theory is the most widely accepted. Testing suggest that many cases are the result of the reactivation of some remnant of the oral herpes simplex virus (HSV-1). That's a cold sore virus that most of us (probably you) happen to carry, dormant, on nerve tissues. (This is not the same as HSV-2, the genital herpes virus.) The facial nerve swells in reaction to the virus, cutting off signals to the muscles. Why does the dormant virus get reactivated? No one knows. Stress, illness, trauma, bad karma. I had a flu shot the Wednesday the symptoms started, which made me suspicious, but studies have refuted any

connection. Charles Bell first described it nearly 200 years ago. And still we don't know.

As there is a 1 in 60 chance you will find yourself at A&E in this sort of predicament, it might be good to know to ask for two medications typically given to Bell's Palsy patients. One is prednisone, a steroid. The other is an antiviral such as acyclovir. As an article in *American Family Physician* put it: 'Approximately 70 to 80 percent of patients will recover spontaneously; however, treatment with a seven-day course of acyclovir or valacyclovir and a tapering course of prednisone, initiated within three days of the onset of symptoms, is recommended to reduce the time to full recovery and increase the likelihood of complete recuperation.'

However, this treatment course is not wholly accepted. Studies tend to support prednisone, though not with complete confidence, and tend to cast more doubt on acyclovir. Still, I recommend you get both. I was given only the prednisone by the A&E registrar (when he found out I was lecturer, he looked a little worried and said, not quite joking, 'I hope not of medicine'). I didn't get the acyclovir until I had a follow-up with my general practitioner a week later and by then it was probably too late; he was annoyed that A&E hadn't prescribed it. Prednisone made me (even more) prone to outbursts of anger. And because I could only move part of my mouth, I had trouble articulating my words, getting people to understand me. I'd call a shop about something. *What?* they'd ask. *Can you repeat that name?* Whatever my other failings, until then I was always able to communicate. The combination of the prednisone, my frustration and the pain was a potent one. After one difficult phone call I slammed my laptop shut in such frustration that I destroyed the hard drive. I'm writing this on its successor.

You will perhaps not be surprised, as I was, that my face showed no sign of recovery by the day of my reading in the US three weeks later. My body had no interest in my professional timetable, nor in the optimistic recovery statistics. At some point in the first month my hearing returned to normal. But along with ongoing complete paralysis on the right side of my face, the loss of taste continued, as did the headache, earache and dizziness. The room stopped spinning—but a strange lightheadedness became for months and months a daily companion, giving the world a kind of distance.

The readings were a farce, of course, though everyone pretended otherwise. Family and friends came to the Ivy Bookshop in Baltimore, some from as far as New York. Half my face wasn't working. I could barely articulate my name. But I stubbornly stood there and read poems for half an hour. I made a joke of it. 'And now a poem as read by Sylvester Stallone.' People were kind. They laughed. They bought the book.

The fact is, I was impatient with illness. I wanted it gone. I wanted to be myself, to be seen as myself. I had taken to wearing a pirate-style patch over my right eye to protect it from dirt, dust, leaves, inadvertent pokes by my young son (I had no protective blink reflex). While in Baltimore, wearing the patch, I dropped by a friend's house with some of the other old friends in town. We fell into the old playful rhythms and it was the most normal I'd felt for a long time. There was a parrot in the house. One of my friends put it on my shoulder and took a photo.

I returned to my teaching job a month or so after my diagnosis, declining my department head's offer for more time off. I was oddly worried that it would in some way put my job at risk. It was a heavy teaching year. We were moving to a new building in August, which required sorting through eight years of files, packing boxes. I was coordinator for our English programme.

I was sleeping hours later than usual whenever I could—I used to wake easily at 6:30, but now my wife let me sleep quite late on weekends, so she bore the brunt of the kids' early rising. I still couldn't move the right side of my face. I was in pain and dizzy, constantly exhausted. Still, I kept it all going. I was in a hurry to get better and to be seen that way.

Needless to say, I wasn't at my best that year as a teacher. I forgot meetings. As English coordinator I barely held it together. But I pretended I was well enough to carry on, and eventually people started to believe me. I took occasional short-cuts. To make my life easier I scheduled a writing workshop at a time that, as I found out later, conflicted with a colleague's class. There were a couple of other options on the timetable but they would have vastly complicated my life, made things much harder. The overlap affected four students. When I declined my colleague's request to shift the workshop she yelled at me with such vehemence and contempt I was uncharacteristically speechless. But why shouldn't she spit her ire at me? I was fully recovered, wasn't I?

Domestic life continued in our semi-rural home. After a bumper crop of pumpkins we watched the vines dwindle until they nearly disappeared. We popped the misshapen bells from the vines, even the ones grown the wrong way over the fence into the neighbour's paddock, and piled them on the porch; we planted lettuce, beetroot, carrots. The whole garden had a kind of tired, morning-after wrinkle, a bed left unmade by someone headed for the hospital half dressed. An inflamed nerve pressing bone, no signals running through the wire. A face sort of leaning down and to the right. What's a face? Only who you've been. My wife did all the digging, shooed me to the couch, the hens to their run. A matter of waiting: would the lettuces survive the frost, beetroot grow, broccoli flower, chickens return to the lay, pumpkins self-seed to rise next season from shrivelled vines to the fullness of former selves? Nothing to do all winter but let time take its time. Two months, then three. The world half-frozen. I offered it half a grin. My wife, mulching rows with priestly patience, searched for signs of life. Shopkeepers treated me too kindly, like maybe I was an idiot. Anything seemed possible. I kept one eye open.

At this stage in any drama, you will expect some good news, then a reversal, and I will not disappoint. My right upper lip started to move slightly in July. Gradually I saw more improvement over the next few months. I could eat without biting my lip. I could with some effort partly move the right side of my mouth. Most importantly, by October I could close my right eye (no more swimming goggles in the shower to keep shampoo out of my eye). I had a blink reflex, too. Finally, after six months, I thought I was home free. But then the improvement slowed. A new problem emerged. Essentially, the nerves had been paralysed for so long that when they came back to life they mis-wired. This condition, called synkinesis, is common for slow healers, for those with particularly deep palsies. When I closed my eye, the right side of my mouth visibly pulled upwards and vice versa—when I smiled, my right eye closed. When I ate, my eye watered: you can still tell I've enjoyed a meal because tears stream down the right side of my face. My right eye became noticeably smaller than the left. During the worst of the facial palsy the right side of my face had drooped, as if I were the stroke victim I'd thought I was. Now, as though my body had worked too hard to correct the problem, the synkinesis pulled the right side of my mouth oddly upwards against gravity. I gave a lecture in this new condition. There was

no normal connection with the students, no energy in the room, no response to my efforts at humour. They just gaped. Just as things seemed to be improving, I looked again like a freak.

Enter a sort of saviour. I was meant to present at a conference in Boston in March 2013, so I scheduled a stop to see family in Baltimore. My wife suggested that I investigate whether there were any Bell's Palsy experts at Johns Hopkins Hospital. I did and there was. I emailed him, a plastic surgeon and ear, nose and throat specialist (it turned out his wife is from New Zealand). He agreed to see me. I showed up at his office on 28 February and within minutes of examining me he recommended outpatient neck surgery. He planned to cut some of the platysma muscle to release my face and reduce a lot of the tension that was causing the right side to pull upwards. It was Thursday, and I was leaving for Boston the following Tuesday. This was a man who had patients to him from all over the world. Nevertheless, the next day he was cutting my throat.

The surgery made an immediate difference. I left his office with a face that looked abnormal but much more relaxed. Thirty units of Botox also helped my appearance (temporarily). My Hopkins doctor—to whom I am incredibly grateful—referred me to a physical therapist who showed me a series of facial exercises. For example, I had to say certain phrases and try to prevent my eye from closing while I talked. Three times a day for at least seven weeks I had to give myself visual feedback to retrain my face to act normally. F, V, B, M—these letters in particular tended to cause my eye to close, to flutter heavily. *Feed farmer Fred* I'd say over and over to the face in the mirror. *A victory for Victor. Make Mary's mother more milk.* Eventually I could talk without my eye fully closing at every second word, though even now when I'm tired or anxious—sometimes speaking to a new acquaintance—it returns.

Meanwhile, other symptoms started to worry me. In addition to the headaches and earaches, my hands trembled. The vision in my right eye was blurring, making it harder to read the computer. I had tingling in my chin. At various times I was certain the facial palsy was some indicator of a deeper neurological problem. Given that Bell's Palsy is a diagnosis of exclusion, this wasn't completely out of the realm of possibility, and the internet loves to feed on medical ambiguity. On Monday I was sure I had MS. By Wednesday I was certain I had early signs of Parkinson's. A week later I was convinced I had an acoustic neuroma.

These symptoms continued for another eighteen months. Finally I asked my GP to refer me to a private neurologist, accessible because I had private insurance, something I'd not thought to use earlier. The neurologist did a thorough assessment. Nothing wrong with you, he said. To be conservative, he arranged an MRI (but only after a wait of six weeks during which I had to stay off paracetamol and ibuprofen—'the junk,' he called it—to ensure I wasn't suffering rebound headaches). The MRI result was negative. Before I left his office, in Wellington, he dictated his notes in front of me. 'Dr Walpert,' he said, 'is still getting accustomed to his new disability.' My GP put it more bluntly: Aside from the obvious—residual facial paralysis, synkinesis, related pain—my only problem was anxiety. 'The new Bryan is different from the old Bryan,' he said. 'You've had a shock to the system.'

If you're like most people, you'll pretend when you see me that you don't notice the distortion in my face. Or maybe you'll be kind and tell me I don't look that different, or even that I'm looking better. I appreciate it—I have improved a bit—but there is no getting around reality. Kids routinely ask about my face. On a family trip to the US my son got teased on the playground about my eye: the boy asked my son if New Zealand was an alien planet. A New Zealand poet, a woman I hadn't seen in five years, touched my hand, looked me in the eye, and said, 'I'm not saying you're not now, but you *were* a very good-looking young man.'

Do you think I don't know there are many ailments far worse than Bell's Palsy? I am otherwise, as my GP put it without irony, 'a picture of health.' I thought about his use of 'picture.' How important are our faces? According to a 2011 article in *Philosophical Transactions of the Royal Society B*: '[H]umans readily draw a number of conclusions about the personality attributes, appearance, emotional states and preferences of complete strangers solely on the basis of facial cues.' I don't know whether to mention the history of my face to someone I haven't seen in years, or whether to let it go—for their sake or mine? I avoid photographs and, if I can't, try not to smile. Facebook? Think about the very name of that site—not sure I'm the target audience. People post photos of me sometimes and I cringe. I try to get used to the fact that I don't look quite like myself any more, that some people react to me differently—I can see the hesitation, the unspoken query.

And I wait to see whether the whole thing will strike again. Though one in 60–70 people will get Bell's Palsy over the course of their lives, roughly one in 14 of those who have had Bell's Palsy will get it again, either on the same side or on the other.

I started out in a hurry to get better. Seven years after losing my face, I am in limbo. I'm not sick, but I'm not who I was. A counsellor encourages acceptance: 'But how is the new Bryan the *same* as the old Bryan?' My Johns Hopkins doctor suggests a fairly substantial facial reanimation surgery that would require transferring a muscle from my leg to my face. But I worry I will end up simply another not-me, just different from the current not-me. Accept or refuse. Resist or embrace. What would you do?

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And why on earth am I telling you all of this? I think it's because Bell's Palsy is, in the grand scheme of things, a nothing that feels nevertheless like a something. I think it's because I hate an elephant in a room, so I'm the one who points at it. I think it's because I'm invisible and want to be seen again. Me, I mean: the guy behind the face. What better than this? We're equals here. No videos, no photos. Just old school—words on a page. Here you don't have to acknowledge what I look like or tell me I look fine.

Still, it's hard to hide behind the page forever. Some day you might find yourself cornered in a conversation with me at some literary event, with no ready excuse to walk away, your glass still half full. It's okay. You don't have to look at me when I talk to you. Just listen to the sound of my voice.