Alistar's Story

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MY THOUGHTS – EPILEPSY

I was first diagnosed with this malady at age 16. I am now 78. An accident at birth, they said. My mother completely denied she was complicit. After all, she was a registered nurse and midwife to boot. I did emerge into the world loudly announcing my arrival, gripped by a pair of forceps.

I played rugby, had a smash on a 50cc motorcycle, and had the odd fight at school. Could one of these have been the reason? There was no such thing as three weeks off, for a rugby concussion in those days. No, no, it would have been from birth, they said. Maybe that is why I stared vacantly out of classroom windows, lacked concentration at school, and didn't always follow the teachers' instructions. Pretty normal, I thought. Who can concentrate their undeveloped brain for a full hour of classroom lessons?

One day I remember picking up a prescription for my Mum, receiving it in my outstretched hand which seemed to have lost connection with my brain. My hand remained stuck out zombie-like until the neural link was restored when I went happily on my way. Some would say I was always a bit blank-brained, but boys will do that to boys, as passing compliments was then not a vogue thing to do. That *petite mal* was when I was 16. I never thought any more about it, other than, 'that was a bit strange'.

Some months later came the big one, a *grand mal* – now known as tonic-clonic. I was carted off to the hospital, where in a hazed state I went through all the gizmos to get my official diagnosis. What a bummer! I was in denial, particularly when told I would need to take medication for the rest of my life. This strange frontal lobe thing would bug me forever. The pain in my arse from being knocked over at rugby went away. I'll show them, I was thinking. I'll take their bloody pills for a while, then stop. Nothing wrong with my brain. Positive thinking will kill this insidious thing. Yeah right!

In those days, my nurse Mum would handle any episode by shoving a safety pin through my tongue, to prevent me from swallowing it. A remedy since discredited. The painful swollen tongue was worse than the affliction. It didn't happen much, so I am one of the lucky ones.

Medications or their application weren't as sophisticated as these days, which are still relatively in the dark ages for this disorder. I was prescribed Dilantin. These pills seemed worse than the illness -ooh, that word, I don't like to think of myself as unwell. I slept through the University years, forgot stuff that appeared in the exams, and mucked up some well-planned rugby moves. I thought, bugger the medicine, decreased my dose, nothing happened, so then flushed the rest down the toilet. Still, nothing happened. I felt like a free man or callow youth, as it turned out. I was pill-free and seizure-free for about 20 years. Not too many people knew I had a problem, but it gnawed away in my mind, big time. I got married to a beautiful caring woman. We checked with doctors that it wasn't inheritable. Of course not. Our kids turned out much brighter than me and inherited some lesser traits, but no epilepsy.

I had trouble admitting this *secret* of mine. I never declared it when applying for jobs, and never talked about it, as I felt sub-human. After all, who wants to know people with a mental affliction? Even I didn't want to know that part of me. I am fortunate in that I have always had an extended warning that I wasn't right. Muddled thinking through a fogged brain told me I would get through this. Wrong. Now it is straight to bed, after toileting and taking a magnesium tablet, preparing myself for the ambulance crew by having a bare chest for the heart monitor. I had a good shirt cut off me once and want to preserve my clothing.

As an old (only defined by age) and hopefully wiser fella, there could be other triggers for a fit, such as a stuffed heart, stroke, covid-19, or just an old, tired body saying, 'I give up.' In my case, the pain of rheumatoid arthritis set my course for the last 8 years. I'm reasonably fit for my age, by cycling, walking, and maintaining the home while thinking about weights and stuff I don't like. More young people burst past me on their later model flash bikes now, as I struggle up hills puffing my guts out. So, I do more of the casual flatter stuff visiting beaches, cafés, and more cafés. Living on the North Shore of Auckland, New Zealand, nothing is that flat. More like rumples in the land.

My medication has been tweaked a bit over the last 8 years, as I have been having an episode every 9-12 months. I wonder if I can even drive a car, it has been so long. I have never had a problem when out biking, walking, or on holiday here or overseas. No longer needing to strive for business targets, more relaxation, and a lack of stress do wonders. Also recognising that when a bit tired, a rest or nap might just be the remedy. Perhaps I was meant to be a lazy sod. I don't do time trials on the bike anymore and got rid of the speedo to boot.

There is no gain in surmising what life might have been like without a funny brain. It is what it is, and we all find ways to deal with it. For me, it is avoiding stress, consuming real food, with plenty of fruit, nuts, veggies, meat, and the occasional red wine, and enjoying social occasions whenever possible. I regularly take a magnesium tablet and vitamin B complex tablet, which I reckon staved off early signs of fitting e.g. flickering eyebrows, and loss of full thought connections. This is in addition to prescribed medication, which I now believe in. I am no longer the smart uninformed ass; I was when younger.

Anyone with this lurgy needs to take the bull by the horns, research it, and do what you can do to lessen or prevent future seizures. There are so many variations, so many different causes that one size doesn't fit all, but you are in the driver's seat, and know your body better than others. It is no more a weakness than not having firm abs or bulging muscles. Listen to your doctor and keep up the meds. There are far worse lurgies out there that other people cope with. Think how lucky you can be.