

From the time I started to know something was eating away at me, I started making notes.

I never used to think about me in the way I do now. Each day came and went, I planned and worked through the rolling days, all seemed fine, normal, as it should. Family life and work seamlessly merged and reasonable happiness was the result. Don't get me wrong, there were the ups and down, but that is normal for everyone, that's what makes it normal, but that's the difference to now.

I've always had an average memory, average abilities, just an average me. I was a Primary School Teacher, had a lovely wife and four kids, home and a good social life... as I say an average person, living a good average life. However, I remember the first time something stopped me in my tracks and changed all this; this wasn't anything that you would think would be a cause for concern, it was something I could rectify immediately, but it stunned me more than I can put into words. I got C and G mixed up! Spellings one of those things, we all get stuck, but I couldn't get it sorted in my head, the ability to think, or see what it should be, just wasn't there. Was it C, or G!? It took several minutes and trying the different spellings, before it all became clear and the moment had gone.

This came back to haunt me and again and again. I got more letters mixed. b, d, p, t, m and n and on and on. More strange spelling problems started to appear. I started miss spelling words, like no and know, there and their, and I just didn't see them. I would get letters the wrong way around in a word, such as wait and wiat, and again not see them. The most embarrassing was writing a good number of reports with the wrong gender... him when it should have been her and her when it should have been him; not good! I was having to get my work proof read. I was missing words, although to me the sentence read ok, I just didn't see the problems. This had a major impact on my life. Reading a writing was becoming a mammoth task. Something that used to just flow, now took mind sapping effort.

This started many years ago and kept asking doctors for help, but never managed to get, so this just went on; told stress of work, depression, possible virus! It has been something that gradually kept up on me and for twenty years or more I have had to manage.

In 99 I became ill, wet myself at school without knowing, became disorientated, had balance problems and finally ended up in QE Birmingham. Had test for many things, but couldn't isolate the problem.

The previous year, we had been on holiday in south of France, on the Dordogne River and while out I got a bite, or sting on my right leg. This led to a major allergic reaction. Had to have treatment, but several days later, I was up and about again. I wasn't feeling 100%, but thought this was just normal.

My neurologist thought this may have had something to do with my illness, but then explained that this was like a, hit and run, accident, what had caused the injury, but the cause had now gone. I was diagnosed with left temporal lobe damage.

I lost the use of my right leg and much of my right arm and hand, facial palsy, loss of taste, smell, loss of bowel and bladder function, my eyesight, particularly my right eye was affected, I see a swirling pattern in front of my vision, everything moves. Diagnosed with Neuralgic Amyotrophy.

Treatment, care and time got me back to some normality. I spent a year in a rehabilitation centre and got brace which meant I was back in the land of the living.

The damage seems to be causing more problems and my neurologist said that it was progressive.

I started having seizures and was diagnosed with Epilepsy. Treatment has this under a lot of control.

Balance was becoming a problem. I would get moments where I would get the sensation of falling, as if I felt the whole weight of my body, a dead weight. This would be a split second thing, but would linger for several hours. These still impact me today, but now I'm predominantly in a wheelchair. I've never found anyone that experienced this sensation; like your body turns off.

I was stable till 2005 and then I had a major dizzy spell, although I say dizzy spell it really wasn't a dizzy spell, it was as though my body continually wanted to fall to the right, over and over. Shortly after this I would get buzzing in my head and the pressure would build; it felt as if my head would explode and I would get this strange dizzy spell sensation. This left me on the floor, or if I was quick enough, lying down before I fell. Nausea was horrendous and I was unable to control being sick and messing my self; this is the worst feeling I've had.

This illness was different from the falling sensation that I experienced with the Epilepsy and was very different from any grand mal seizure, I didn't know about it. Also, after a major event, I felt really good, high, euphoric as though as I had been rebooted. Another strange thing about these events is that I've broken, fingers, wrist and had a few bad bumps, they didn't worry me at all. I think I could have cut my arm off and I wouldn't give a dam. I quite like these seizure, for these reasons and I sleep for ages.

However, these new head surging dizzy spells come on with a vengeance, the build of pressure in my head and the escalating buzzing in my head told me what was coming. I was left for many days, in bed, unable to eat and trapped with the inability to move.

This was later diagnosed a Menieres and the medication took a long time to get right, but it seems to be well under control now.

With each event my hearing became worse and Tinnitus was, and still is, a major problem. I lost all the hearing in my right ear and much of my left. I had a Bone anchored hearing aid fitted and this has helped a lot. They would like me to have a cochlea implant, but it means I would lose any of my natural hearing that I have left. I can't decide!

Major muscle spasms and tremors give me great pain and I have daily morphin to help, which it does. I also have neuralgic pain, like toothache in my face, eye, teeth, ear and all down my right side, again Gabapentine helps greatly.

I was depressed, but what else would anyone expect and this had a major impact on my character, I was angry, frustrated and I couldn't deal with anyone. This got so bad that my wife left me and my children started to keep away. Knowing what I was like didn't help and doesn't help now. I know I'm different, but knowing doesn't stop it, it is out of my control.

I now live in a converted garage, that I rent. It is the garage of a teaching colleague of mine. They offered me the accommodation if I was happy to pay for the conversion to meet my needs. I have everything I need. I find getting out hard. I fear meeting people for their sake not mine. I have found that going out in my trike wheelchair helps, I can avoid everyone.

Finn, is my support dog, but he is more of a friend and I've had him for five years now.

I remember my grandad, not well, but can see him now, in a small room, in one of those places back in 1967. The room small. Just big enough for a single bed and wardrobe. I see him sitting there, on the bed, smoking his pipe. Not looking at me, dad, or out of the window, but at the blank wall in front of him. Slowly rocking like a lost gaged animal. He was a small man, plain. I can not hear his voice, but I can still see him. Just the once, but I remember. He died alone and senile.

Dad, mum said, died with the fairies.. we use to laugh at this, because we all remember him saying things that were off the wall, that was when he was not angry and ranting. 'Send them my love and tell them yes' this became his ending and repetitive catch phrase. Is this for me?

I have come back to write some more notes;

For a while I have been stable and able to manage my life. I like my independence, but over the last few years, I'm starting to have more problems, so I need to write them down, before I forget.

I'm going to write them as they happen, the symptoms as I experience them, so they may not make much sense, but I'll try and clarify what is happening. I do not know if this will help me, but someone may make sense, someone may not what I am saying about. someone

1. I feel as if I'm getting smaller inside my head. There was a cartoon in the comic called Numskulls; this was about little characters that lived and controlled different parts of your body. The control centre was inside your head and the controller would look out of your eyes, so see the world from a distance. This is how I'm starting to see the world, from a distance, my hands, arms and feet, seem detached. Sometimes this is worse, but when normality is here, I do not have this sensation.

2. I get the sensation of travel sickness, like a nausea in the pit of my stomach. I can remember being travel sick on a bus trip when I was at school and that is the feeling. However, with this I have this strange feeling of doom, I'm frightened, like something is coming. Feeling sick doesn't last long, but fear feeling lingers.

3. My Mum and Dad passed away a long time ago, I'm not sure when, which is odd, but I get this feeling often that my Mum is next to me; over my right shoulder. I don't see her as such, but I almost sense, or see her in the corner of my eye, a shadow. I don't hear her, although I do talk to her. I'm hoping this is normal.

I often seem to get flashes of things passing my vision, but I have had this for a long time. As though something is scurrying across the floor, a spider, mouse. I know it's not real, because I never see anything, but I always get caught out. The other type is almost like a movement in my peripheral vision, of an inkspot; like what you would see if you dropped a splash of ink into a bowl of water. I never see this in any detail, there here and gone just as quick.

4. Stopped driving.

Starting off and slowing down started to become a conscious effort. Turning right, or left also becoming a problem, again something I didn't really think about now is something I have to consider. Times when out, suddenly total loss of where I am. Only short time, but totally no idea, everything seems unknown to me.

5. I better at seeing words than trying to see them in my head. I get stuck with simple words, just can not see anything in my mind. predictive text helps with this. The other bit is missing words, so a sentence does read right. I still skim read, but find that hard to take it in.

6. Numbers in sequence. finding trying to work out what comes before or after, like what day with 12, 23 is.. can't work it out simple. Same with which way to go when taking away or adding numbers. Not always a problem, but sometimes it's a real problem.

7. I have two clocks to help me remember tablets and appointments, but I can not see the time will on the old clock as the digital clock. but I do get stuck sometimes with what time is coming with digital one.

8. Hearing sounds in distance, but strange memory sounds. We lived in Tamworth and Sunday the church bells would ring. I hear them every now and again... far away, but there.. Steam train at station, clicking of outdoor loo latch, it was big a metal and clattered. Voices chattering, but not

making any sense, like the children in class, running water. I find sometime I find myself becoming aware of them for no reason. Doesn't worry me, but is strange.

9. flat back of things I haven't thought about for a long time. I remember my first day at infants. The concrete steps, the pegs, and pictures, and going to sleep after dinner. Things are appearing as if pages in a book. There one minute. Same with smells and taste. Nice

10. Ghost over my grave. Get strange shiver feeling. Can get this days before going somewhere. If I get know something is coming up, appointment, or thought of going out. Days before.. waiting, fear.. face goes numb, affects swallowing.. have to think about it

11. Strange taste. This is unknown nasty taste. Metal mixed with burn toffee and raw meat. Not a taste I know. Makes me sick sometimes. Not know what brings it on.

12. Taste changing.. clear sweet or bitter. prefer bland porridge.

13. Get stuck with swallowing sometimes. when I become aware of it. Like thinking of breathing. Sometimes I can not swallow and have to give up, but later no problem

14. Wake up gasping for air. Like stopped breathing. horrible sensation.

15. Learning new things hard, impossible. I can not retain information, make notes but can not make sense of them. they do not lead me back to information. Used to play piano but can not remember sequences.

16. Reading stories hard. Remembering what is gone before. if I story in one go that is ok. but if I come back to it. it doesn't work. I listen more to stories, but find I end up just listening to conversation and miss story.

17. Like songs, seem to be able to remember them well. like singing, but not sure Finn does. Thinking of old songs more and more. make s me happy. good think

18. I've heard people talk of fog, my fog is like a pressure in my head, that seems to block everything else, I can't think of anything clearly, can not plan, or what to plan. what to do, what I should do, when I should do thinks just getting more squashed out. Nothing is clear. The more I am aware of it the worse it gets and controls me. Not like falling into blackness, more like getting smaller and smaller inside my head, further and further away, so I can not quite make sense of the world. Out of reach out of mind. Can think of what to do sometimes. Like moment of loss. This is the worse moments. Trying to grab hold of life. I know I should be doing something, or should have but what, how, when. feel like a light fading and getting dimer and dimer.

19. know there is something eating my away from the inside, but if I know can I be ill? Want to fight, but feel I can't. Terrified of what I will become inside my head. feel I'm being locked away. Don't want to see you, but you not see me. How do I stop feeling hopeless.

20. Can type now. use to touch type, then noticed always selecting wrong letters. It was though my fingers had replanned, so when I thought one letter, I would select another. Not close letters on the keyboard, just wrong letters. Started one finger typing, but this is slow, like double checking each letter and still make wrong letters.

21. Forming letters. left and right. Keep getting shape of letter wrong. S starting the wrong way around, or tails like in g going wrong way, cross lines like in t, I put the wrong side. I can see it and know that it is wrong when doing it, but still have to work at correcting. I noticed this when had to copy picture test. Had problems working out which way lines go. It is left and right, up and down seems ok. Clock drawing was bad, I could see it was wrong and if I could have tried again, I think I

would have got it right. I have to do things again and again. Hard to get image in head and make sense of it, even when looking at it. Can not make sense of it well.

22. Been working on memory training. Going over months. Ok now going through the from beginning, but hard when have to think what is after this month, what comes before. it is going backward and forward. Can do it but it takes time. Did not before.

23. My hair, beard and nails growing. Can not cut. It is not that I can not have cut them, but I do not want to. It is getting rid of something of me. Sounds mad to me I know. Like part of me. Broke nail and was really upset. Had to file nails. This helped as I did not see them go all at one time.

24. Emotional get really upset by anything. TV advert about donkey. Bad foot and bastard making him work. I was just in bits. Can not control. Crying does clear me, I just get more angry and upset. Need some way to deal with this. Lingers

25. Have mountain trike. Wheelchair with handles. Can get out. Like my own bubble. Finding can not stop. go around and around park. 1 mile and then just got worse. 5, 10 and last time 22 miles. I enjoy this, do not hurt anyone. Listen to music and just go. Could do with goal. Raise money for something. Would like to do long run.

26. Losing focus. I use to have a purpose to each day. Now no purpose. Just seem to day dream about nothing. Mind just skipping over nothing. need a goal.

27. I have always been IT mad. Anything I would search online. Noticing that harding to rationalise my searching. Drifting. Harder to understand information. Takes time.

28. Use to run ukulele group. find playing songs harder. I no the songs, but getting body to go to right chords strange. I know it is wrong and can correct it, but seems to happen more and more. Like singing with playing. Focus on this and everything ok.

29. Like routine. I can do thinks once I get the routine. Problem when anything breaks it. Routine good for each day.

30. Have watch that vibrates to tell me time of things to do. take tablets, wash, eat, people coming, everything is run by calendar. Feel it is running my life. Use to use diary when teaching. Whished I could do that now and not calendar on computer.

31. Thinking of brothers. Eddy had gone. I can not remember when. Like it was yesterday. Sad. got me down. bad day. Same with Mum and Dad. Feels so close, but remember at grave.

32. I become aware that I am going around in my room. Do not know why. Just suddenly aware. Feel like walking into nothingness. Nothing to hold onto. When did I start walking what started it of.

33. Notice big word problem. Like brain splitting word up, like when at school learning bigger words. Not big problem, but words splitting.

34. Days totally different. Good feel like I can climb mountain. Bad treacle everything hard slow just blacking.

35. write emails, but have to write text over and over to make sure it is ok. This is the same when with anything I write now. But I can get there just takes time. Spell checker good. All the time words and grammar come up. but can work with that.

36. Dreams and awake seem to be close. Sometimes wonder if dreaming. Dreams are always so bold and totally strange.

37. Been really aware of today. Now. Can not stop thinking of today. If I know now, will there be a day when I do not no? Fear of tomorrow. Here but not here. Feel like going down 2 road side of each other. Do not know which I am on.

38. Feel like demon inside. fight my own thoughts every day. If I could stop fighting and deny them being there. would this help. Can not stop thinking of future. No good. Need to think now but how. I can not control this in my head.

39. Say little as possible. ask me if I am ok. Say yes and smile. feel like being watched all the time. waiting to make problems. I have to work hard at what I am saying. If Barry says something, some of it is not there. I do not know what it is. I want to talk, but thing I will sound daft or just going on and on.

40. Alone, but never so lonely as now. Seem empty. Want a hug but no will cry. I need to cry but do not clear me. Could scream. miss love and being loved

41. Notice repeating myself. think I have done this all the time. Think we all do. But does not help remembering. when I stop I forget its gone.

42. Told have dementia, but can not get understanding of it. If I know I have problems how can I have it. Unspecified. what does it mean. Said 62 so early. Scan and test and family show it. This has been long road. Can remember start, just now get hazy. but is that me locking myself inside with it. Want to try anything. Said try anything. Do not want to sit and wait. Will I get a time when I do not no I have it. Feel like coin. one side dark the light. Everyone must fight it. rage against it. Do I take it and live without thinking of it. Would like that. If can have treatment, I would pay to try tablets. I have nothing to loss. If I have it ok, just leave me in peace.

43. I can not lateness. If someone is coming, they have to come on time. I panic, worry, stress get alsorts of things in my head. Knowing this doesn't help. Waiting for the doctor, in an appointment, with others is a nightmare of heart beating pain. I get anguish days away before the time and it just gets worse.

44. I fear things that I did not before. I can get panic just by thinking of this. In Mri scan, I could stand it, could not go in. I feel my shoulders and that is it. I panic at the thought now. It the same for high things, small dark space, going out and the strangest is deep water. I do not go on deep water, but the thought of it is trigger to melt down.

45. Being sick a lot. Strange taste. metal or burnt metal. not when I eat, but after. Instant makes me sick. I struggle to eat, no swallow some times. Think this because fear of being sick after. Like neck want let the food go down.

46.