

# Brain Tumour Humour

(MIND THE GAP!)

AHTUDOR | 2019

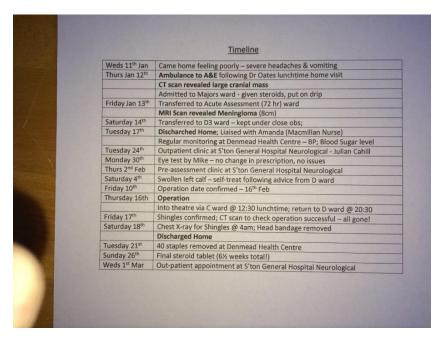
#### Hello

This is an account of my journey from shock diagnosis of a very large brain tumour (Meningioma), through its stabilisation, surgical removal and onto the road to recovery.

The stages of my journey, as laid out in this account are:

- Intro (it's been quite a year)
- Pre-diagnosis (the signs were there)
- Diagnosis (oh sh\*t)
- The Waiting Game (6 weeks without sleep!)
- Operation (drill, hoover, put lid back on)
- Recovery (he's still here?)
- All clear (thank f\*\*k)
- New me (mind the gap)
- Giving Something Back (stop press!)
- ➤ And Finally...

Here's the timeline of the significant events covering the 7 weeks from flash to bang, in 2017.



# Intro (it's been quite a year)

2017 has been a year of firsts. It's the first time I've...

- not been able to talk or dress myself (whilst sober!)
- been in an ambulance
- stayed in hospital

- had a CT and MRI scan, or chest x-ray
- taken steroids
- hallucinated (whilst sober!)
- had an operation
- been under general anaesthetic
- broken any bone
- had a blood transfusion
- had staples fitted/removed (40 off)
- used a catheter
- had shingles
- used a commode

It's also been the first time I've really contemplated my own mortality, and blubbed like a baby.

It's also been the first time I've been able to stop and fully appreciate the true depth of love, support, warmth from many family and friends. It has been a truly humbling experience. It's only me!

# **Pre-diagnosis (the signs were there)**



One of my last photos taken about 3 weeks before becoming ill

I've been asked many times what were the symptoms – how did you know you had a brain tumour?

Well I didn't until it was in the process of killing me! However, in hindsight there were symptoms which had been building over time.

Apparently it could have been growing over 10 – 20 years (mine was a right parietal, Grade 2 meningioma, 7cm max width). I'll never know when it started to impact my abilities or performance at work, so I'll never know what I could have achieved if it hadn't appeared.

I've split pre-hospitalisation into two phases of increasing intensity:

- > 3-6+ months prior to diagnosis
- > 24 hours prior to ambulance

#### Symptoms 3-6+ months prior to diagnosis included:

- Increase in mild headaches, exacerbated by long driving journeys, say 1 or 2 per week. Often accompanied by a flashing halo of lights in my peripheral vision
  - o My diagnosis was too much rugby played at school & getting older
  - o **GP** diagnosis was early onset arthritis in the neck, not really treatable
- > Feeling more tired, and having less energy, especially at work
  - My diagnosis was getting older
- Occasionally getting lost whilst driving, missing turn-off's from motorways, taking wrong turns, once ending up outside the wrong house when driving home from work
  - o My diagnosis was getting older, possible dementia?
- Occasional feeling of weakness in left leg after long drives
- Sudden 'dropped foot' whereby my left foot slapped down more whilst walking
- Occasionally taking the wrong turn whilst out walking around the village
- > A colleague at work noticing I was limping when walking down a long corridor
  - My diagnosis it was as a result of tweaking my back in the garden, doing a 10km charity walk, and getting older
  - o **GP** diagnosis from push/pull tests was nothing wrong
- > Feeling of intense itching all over body, especially when sitting or lying

One time driving on the motorway I needed to brake suddenly, but couldn't get my left foot onto the clutch quickly enough and the car stalled. Occasionally when driving on the motorway my left leg felt 'odd' – heavier than usual and feeling less responsive.

Occasionally at work if I was having a busy day I would develop what I called 'flashy lights' which were usually an arc of kaleidoscopic lights in my peripheral vision. When I recognised and saw the onset of these lights I would eat a fruisli bar/banana/Mars bar and drink some diet coke, and take a couple of paracetamol and they would soon disappear. They never

reappeared on the same day. I learnt to always travel with a spare fruisli bar and paracetamol tablets with me in case they appeared away from my office.

If I had a particularly heavy meeting I would sometimes eat a snack and take the paracetamols beforehand to ensure I didn't have any develop during the meeting.

#### Symptoms 24 hours prior to ambulance included:

- Intense headaches, which made me wince with pain
- Uncontrolled, repeated vomiting
- Loss of control of left arm and left leg
- Loss of balance
- Confusion, Loss of ability to talk
  - My diagnosis stroke?, dying
  - o **GP** diagnosis was get him to hospital immediately by ambulance

Apparently as I was being helped into the ambulance I asked if I needed my passport (I remember thinking I might need it to prove who I was and that I was British, to ensure I could get NHS treatment!).

Remarkably, I had driven to Farnborough and back (40 miles each way) and done a full day's work on the day I fell ill (Jan 11<sup>th</sup>). On getting home I went to lie down on the bed and felt really rough, with a worsening headache. I soon started vomiting...

If I'd started vomiting a couple of hours earlier I could have been driving on the motorway, or stranded in Farnborough, both of which would have been far worse.

# **Diagnosis (oh sh\*t)**

The following pictures were from my first visit to hospital via the A&E ward, into the 72hr assessment ward and onto another ward. In all, my very first hospital visit lasted from Friday to Tuesday.





No sleep till Brixton! It was impossible to sleep as there was always beeps, bangs, people talking/snoring or shouting, etc. Visits from the family were a welcome relief.

On Sunday a nice young doctor came round to discuss things - nothing new, but he confirmed what I've got was 'a tough hand of cards but absolutely among the best ones to get'.

Apparently the steroids can make you go crazy so he was pleased to see me doing a Sudoku.

It can also raise blood glucose levels, so I'll be getting that checked occasionally. He said the Southampton unit was the best in the country so I'm absolutely in the right place.



On Monday another nice, well informed doctor just came round. Nothing really new except more details that the mass is 'a big one', and that the problems were being caused by the swelling caused around the edge of the mass as it pushed on the brain. The danger is the brain being herniated (pushed down the spine) as it has nowhere to go from the swelling - which is life threatening. Apparently this was showing signs of starting to happen. They are happy the swelling caused around the mass is being reduced by the steroids - not the mass itself - while my symptoms don't return so it's all stable and has given them the time to decide how to proceed.

She is no expert but said the likelihood of taking it out easily depends where it is and what is around it, as it is a large mass. It is on the edge which helps. They will decide in S'ton tomorrow. At least she thinks that as I'm not an emergency they will timetable my treatment for the right surgeon at the right time, which I will find out tomorrow. They might want to transfer me down there beforehand if they want to do any more tests.

As she isn't a brain expert she couldn't comment whether I would make a full recovery as the brain is complex and it depends where my large mass is and what they have to do to get at it. This is quite common, and I'm in the best place possible - mixed news I guess.

Reading about it online calmed me down - and I actually had a good chat to the chaplain which helped. Bottom line is that it's not life threatening, and most of these type of tumours are operable and common, especially in the over 50's. They don't have to take it all out - just enough to stop the swelling, and as it's large it has been easier to spot.

I just want to get on with it now. What happens, happens but something has to be done, and they've caught it early enough before any lasting or serious damage has been done.

After talking this all through with my family its good how as it gets closer I feel like I'm getting to a place which is like 'grow a pair, get on the roller-coaster and lets do this f\*cking thing!! I'll be thinking of my 'coming out' event watching the NFL highlights on the sofa in my new Packers shirt with a clean bill of health and very short hair! All helping me stay calm at the moment.

# **Snapchat** conversation with daughter



On Tuesday I spoke to another doctor- nothing new. She will be chasing up the S'ton Neuro unit this morning and expects to get back to me herself with the outcome this afternoon. She is then expecting me to be discharged into their care at some point. She is happy the steroids appear to be working to control the symptoms.

I'm just doing texts/snapchat, reading, taking pills, giving more blood, and I've opened my bowels! Cuppa just arrived, and just waiting really.

# The Waiting Game (6 weeks without sleep!)

6 weeks on steroids meant I couldn't sleep other than occasional 10/15 minute naps. Therefore I would spend the nights downstairs on the sofa, wiling away the hours between around 11pm to 7am watching tv, reading papers, doing a jigsaw, watching films and documentaries, etc. I couldn't read my book as I couldn't concentrate for more than ½ a page.



Here's the jigsaw which kept me busy for many hours. Apparently one evening my wife and daughter heard a load of pieces fall off the table. I'd fallen asleep so quickly my head had hit a pile of pieces sending them off the table!

I also was constantly hungry, and got into a routine of interspersing the night with the following snacks every hour or so:

- One piece of bread & marmite with a nibble of cheese
- One packet of Rivita
- A handful on nuts and raisins
- A satsuma, pair, orange
- 4 Jacobs crackers (without butter)

I'm spending my time in a cocoon of tv news/sport & weather, papers, magazines, Sudoku's, grazing, and napping. All helping to keep me nice and calm. And my first benefit of all this - we've now also got BT Sport! NBA basketball tonight and Liverpool v Swans on the weekend plus baseball, etc. Good job I'm on steroids to keep me awake for all this sport!





I've got into a routine of a couple of one hour sleeps during the day/evening, plus some very quick naps when I get tired, which seems to be working keeping me sane.

Hallucinating – one of the other side effects of taking steroids was the occasional hallucination. I would see shadows of people looking over my shoulder or sat next to me, or imagine the

cupboards were open when I walked into the kitchen, or see the sofa cushion as a small child or dog. Weird but all part of the fun!

My pre-assessment appointment at the hospital went well. I'm physically ok and there are no apparent issues at the moment. We had a really good male nurse who took us through the procedure and has really put my mind at rest.

I've just had the date confirmed for my operation - it is in the morning next Thursday, 16th Feb. The end is in sight! Was I happy to have the date and get it all over, or poo'ing my pants now there is a date? Bit of both really. But I don't have a choice, and part of me is actually curious about what will happen, so mixed emotions, but my immediate gut reaction to the call was relief, so I guess I want it to happen.

# Got my post-up protection ready!



If it helps, as someone who'd never been in hospital, let alone had a general anaesthetic or brain surgery I thought I'd be bricking it before the op. However, as I knew it had to be done, and that it is a very routine procedure with very high survival rates, I was surprisingly calm before the op, and almost welcomed it by the time it happened.

The evening before I had tea, a shower with the anti-bacterial soap they gave me, then packed my overnight bag. Had last food by 2am then waited for our friend to pick us up at 6am to take us down to the hospital. I felt very calm, not too anxious, and more worried about the operation being postponed than the procedure itself. I'd not asked what would happen in detail (and kept off Google) as the less I knew the less I would worry.

Lord of the Rings 2 went on soon after possibly my last meal. See you on the other side...



6 weeks on steroids meant my face looked like it had been blown up with a football pump!

# Operation (drill, hoover, put lid back on)

I was taken to theatre around 12:30 lunchtime, having arrived at the hospital for 7am.

Jane was told that I may not be able to use my left side or talks properly after the operation.

After around a 6 hour operation, including a blood transfusion, and confirmation I had Shingles, I was returned after the post-op process to the ward around 8:30. Within 2 hours I was texting people to say I was OK!

I can't remember the precise moment I came round, but I can remember being wheeled back onto the ward and grinning as I realised it had all gone fine and I was alive! I appeared to have all my faculties and bodily functions intact, which was a bonus!



Here's the scar, before the staples were removed

The first message I sent to my kids was in Chinese as we'd had a running joke that I would wake up from the op speaking mandarin!

I then sent many family and friends the same message: "The surgery was successful! They removed it all in a 6 hour operation. Removing my mahussive grin may take a little longer!"



The white turban was to keep the pressure on – made wearing my glasses a challenge. I had a catheta fitted which was taking the piss - bugger the op hasn't improved my sense of humour!



Lunch on the day after my op has just arrived and I'm starving! I had orange juice, cottage pie and cheese n crackers! Not Masterchef standard, but not too bad at all. The hospital food is fine and there's a good choice. It wouldn't suit a restaurant but considering they are catering for thousands it's a good effort!

It's been like Piccadilly Circus in my private room today (as I had Shingles I was in an isolation room). I've seen my surgeon - a man of very few words. He confirmed it went well, however as there had been some bleeding during the op, and the extended length of the procedure he would probably want to keep me in another night as a precaution.

I had an MRI Friday evening to confirm there is no additional bleeding and to 'have a look around' - all routine stuff. I'm feeling tired, and a bit sore round the bonce, otherwise good.

My surgeon saw me to tell me my final MRI scan was fine so I'm all clear to go home Saturday!

My head is still sore, but that is getting better slowly I think. A dermatologist visited and thinks I might have shingles on my chest though - which is a pain, but not an issue in the scheme of things. Apparently it can be very painful - but not always. That's why I'm in the separate room. They noticed it during the op.

Obs were all fine - they're not used to happy patients! Going onto hourly obs next. They are giving me 3 lots of antibiotics and back on the full dosage of steroids, but will look to wean me off these as quickly as possible. So another 2 weeks of snacking through the night assuming I heal normally!

Friday night was a better night's sleep and more comfortable thankfully. I got into bed and slept for about 90 mins twice. I also had a chest x-ray at 4am Saturday morning, apparently at the request of the shingles doctor, so nothing to do with the brain op. I was pushed down to the x-ray place, and they did it with me standing up against the machine. It was so late as they did me last cause of my shingles.

On Saturday I was feeling a lot better thankfully. Managed to sleep a bit more, and the head feels like it's more of an ache than a real throb, so signs of progress!

No escape time yet - but there's nothing else to do except remove the turban and check its healing ok, put on a fresh dressing and wave me off!

They've taken the turban off to reveal the scar – it's bloody massive! They put on another dressing, plus sorted my meds to bring home.

I went home Saturday afternoon. It's amazing I can be home 2 days after such extensive surgery. If I didn't have such a big scar I'd have thought I only had a little procedure.

I'm still feeling very tired, but I'm on plenty of post-op medication, so sleep was still elusive. But it's great being home with the family and past the worst. The road to recovery starts here!

I needed help washing what was left of my hair using baby shampoo.

The kids are disappointed though as they'll have to get me Fathers Day cards for a long while yet!

# Recovery (he's still here?)

I returned home two days after surgery – 2 days!

I was on enough medication to keep Michael Jackson happy for a month. Thankfully my nurse – my wife Jane – made sure I took what I needed when I needed it. This included more steroids, more yellow ones to protect my stomach lining from the steroids, and anti-viral's for the shingles.



I was also recovering from the shingles and bruising to my wrist - and a fluid filled scar on my head. It took a good couple of weeks until I was able to put on any clothes over my head. And Jane was washing my hair with baby shampoo for a couple of weeks as well.



Removing the staples the following Wednesday at the local GP practice was no problems at all, although I could feel it drawing a bit.

That's it - the end of all my procedures! My steroids finish on Sunday, then I'm done - boom!!



These are the lovely flowers sent from work after the operation, with a personal note from a very senior board member.

So far so good on the recovery I think. On the up side everything seems to be healing well and all my bruises are fading. I'm finally weaned off the steroids, so I'm getting about 3-4 hours solid sleep each night, and the hallucinations are thankfully decreasing! Hopefully I'll get back to normal sleep as the steroids work out of the system - as I've been on them for over 6 weeks.

We're managing a 2-3 mile walk most days, and I just managed to sit through Lion at the cinema last night (great film).

On the downside, my scar is aching quite a bit, and I have the odd bad day when I feel really drained.

My wife and daughter are being superstars looking after and putting up with me. They've been advised to be with me 24/7 for the first 2 weeks in case I have a seizure/fit!

Overall though it feels like all my faculties and personality are getting back to normal (whatever that is!) which is such a relief, as it means we can eventually get our lives back - yay!!

I had my final outpatient appointment with my surgeon 10 days after the op. That's the last time we saw each other. He thinks he got it all out, but it was an atypical grade 2 meningioma, which means it could re-grow. So I've got a 3 & 9 month MRI's, followed by annual scans for many years - so I get my free annual brain checks! So far I've been signed off work for 3 - 5 months.

My scar/skull is still a bit sore, but the swelling is going down and the ache has finally gone, so all-in-all things are looking good!

I've just got a fierce haircut. I've never had it this short before. It means that unless someone looks closely they won't know I've got a 6 inch scar on me head, so no more hats when I'm out! Apart from my kids singing George Michael songs to me non-stop, it's really helped!

The new style seems popular with the ladies - not sure if that's a good sign as I may have to keep it! Makes me think I've had the wrong haircut for the last 30 years!

I'm going back to work in early June, but can't drive for a year. So my lease car went back early. Thankfully Ford Motors were brilliant and didn't charge me for the early return given the circumstances.

It's a year off driving cause I've got a grade 2 meningioma, which can grow back quicker than a grade 1, which would have been 6 months. I guess they have to assume worst case, and it is seizures they're worried about. Thankfully I've never had any, and my surgeon is sure there's nothing left to grow back, but them's the rules!

Annoyingly I've got a pretty sore back - probably from all the extra walking/sitting/drugs over the last couple of months. Ho hum, could be a lot worse I guess.

A month later and I'm still slowly improving, although still getting very tired if I push too much on doing anything complicated, or walking too far. I feel it's better to push and get tired rather than take it easy!

One evening I found it all too much when the family came round together. It was really draining for me being with so many people I love so much, coupled with the intense non-stop chatting, and occasionally witty bant! I had to go and lie down upstairs away from the commotion. This part is really p\*ssing me off.

#### Every cloud...

I used my concessionary bus pass for the first time today - which I got off the council as I can't drive for a while. Opened up a whole new world!

We kept thinking of Jasper Carrott's 'nutter on the bus' routine!

In the morning the bus was full of wrinklies and I felt really young; in the afternoon it was more school/college kids and I felt really old.

Think I'll stick to mornings in future!

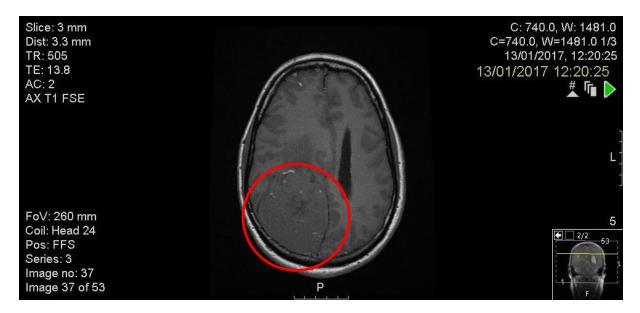
My next MRI scan is in May, when we find out if the neurosurgeon got it all out, and if not what next. I'm feeling a bit anxious tbh, both about getting in the can for 40 mins following an injection, and for what the results will be. All done! Not the most pleasant experience, and the old ticker was going extra fast. Now we wait for the ns team to check it & let me know if they can see more than half a brain!



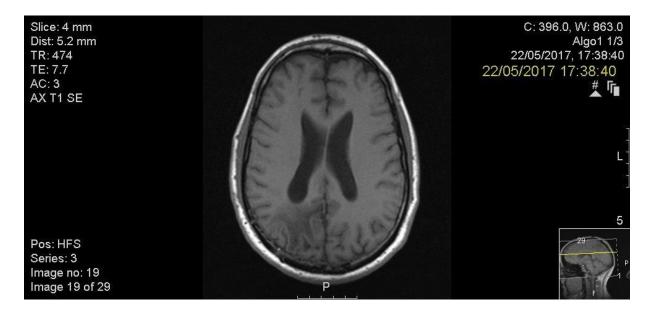
The number of get well cards I received from friends and family was truly humbling – it's only me!

# All clear (thank f\*\*k)

#### Before...



#### After...



These are the before & after MRI scans. The top one shows the tumour bottom left, and the impact it was having on my brain's centre line and the closure of one of the ventricles, which are for blood flow.

The Macmillan specialist nurse said that judging by the before scan it was 'close to knocking me off my perch'.

My MRI scans have been reviewed and my surgeon asked his secretary called me this morning to say I'm ALL FINE! They'll send me a letter to confirm details, but they wanted me to know soonest. Happy days!

My surgeon didn't seem concerned it was Grade 2. He said Grade 2 means there's more likelihood of regrowth, but this isn't a certainty. Mr D also said he thinks he got it all mine out, and removed the offending area of meninges, so there's nothing to grow back. He also said that Grade 2's still grow slowly, so from now on its more a question of controlling any regrowth, as they should be able to see and treat any regrowth before it gets anywhere near the size the original got to.

I was told it could take months to remake the brain reconnections which have been affected before & during surgery. Also the body will channel its energy to fixing the brain, so you will still get physically very tired, very easily.

I've found reading books and newspapers, doing Sudoku's and crosswords, etc, has helped me. Plus a mild walk every day to hear the birds singing!

# New me (mind the gap)

Friends & family now keep telling me I look 'fantastic' as I'm walking & talking like before - 6 weeks after a 5+ hour op, but I'm feeling pretty low, and have to put on a front when meeting people and feel drained afterwards.

Given the scare/trauma of what we went through I feel I should be turning cartwheels of joy given my progress so far, and should not feel sorry for myself.

Reading others experiences on the closed Facebook group 'Meningioma UK' has thankfully shown me this post-op reaction is common and not to kick myself too much!

It does take time to heal from the shock as well. Let alone from the operation itself. Family and friends just see us smiling and up and about like we used to be - they don't see the internal struggle. Takes time to heal mentally as well physically.

We're still in contact with a very nice McMillan nurse who we saw during my first stay in QA. She explains things in words we can understand.

Interestingly before my illness I used to occasionally drink a couple of lagers (don't shoot me!) but post op haven't felt like any. I also don't want to risk the alcohol messing with my reconnecting brain - daft I'm sure.



Less than 4 months after my op I achieved my goal of completing the 10 mile Moonlit Memories walk in Southsea last night, to raise funds for a local hospice. It took about 3 hrs, which included stopping to light a candle in the cathedral.

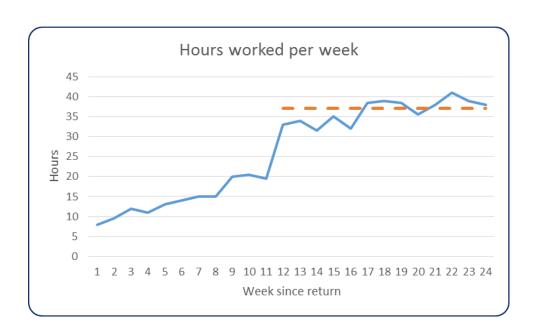
Never has a bacon roll tasted so good!!

It took me about 6 weeks to get over the op. However it took me over 4 months before I could return to work (in software management) part time. It's now 5 months and I'm up to 3 days/week.

The fatigue is more than I'd expected. I got back up to working full-time about 9 months after my op.

My first week was two 4-hour days, and I built up my time gradually, with the full support of work.

The dotted line in the graph below is 37hrs which is my normal amount. This shows I was pretty much back full time after a further 5 months, ~9 months post-op.



Here's my new t-shirt in honour of my evicted m. It's also my excuse for apparently being more inappropriate now!



# **Giving Something Back (stop press!)**

### We made the Portsmouth evening newspaper The News!

By way of saying thanks to the great teams at QA A&E and the Southampton neuro hospital we contacted The News with our story, and by way of their photographer this article was publish across the South Hampshire area as part of their We Love QA feature.

This was the article...



# If you thought that was good...

# We only made the Sunday Times!

This was nothing to do with my illness, but goes to prove what can still be done with half a brain!



# And Finally...

It is now two years since my illness and operation. I have been back at work full-time for over a year and leading a 'normal' hectic life. I find I can perform as well as before, but the subsequent fatigue can be difficult to manage. It often takes the whole weekend to recover from a busy week – just in time for the next week.

We did manage a few days in Venice in March '18. Flying was no problem – and I didn't set off the airport metal detectors as I feared, given that I have three small tungsten plates on my skull.

This was the first time I felt really 'normal' and like my old self...



In August '18 I attended the South West 4 drum & base music festival in London with my daughter. I'd even heard of some of the acts – including Idris Elba doing a DJ set, naturally. Ears are still ringing – or it might be the tinnitus!

Woohoo – I've just had the continued all clear from my second annual MRI – phew!

I realise there are many who don't have such a positive outcome as I have, but I thought I'd share my story to hopefully show that positive outcomes are possible and common.

THE END (for now...)