It could be worse, I could be dead.

(But then again,,,,,)

ONE JOURNEY THROUGH TRIGEMINAL NEURALGIA

IT HURTS!

It really hurts. It really really hurts. You just won't believe how vastly hugely mindbogglingly much it hurts. I mean you may think that cutting off your leg to spite your face would hurt but it hurts so unbelievably much that even Douglas Adams wouldn't believe how much it hurts!

The problem here is one of degree. Those who have suffered the most severe toothache or migraine cannot appreciate the intensity of the pain. Maybe childbirth comes close but I wouldn't know. The only way to know is to have it and I wouldn't wish that on my worst enemy (in my more charitable moments)

There seem to be several varieties, some people just getting stabs of pain and the lucky ones, like me, getting a combination of stabs combined with continuous searing pain that lasts for hours. (Atypical its called) Cutting yourself hurts. Imagine doing that to your face with a VERY big knife or maybe a saw for hours on end – nice.

Again if you are lucky, the whole thing can be controlled with drugs and be made manageable. Naturally enough, mine (what a whimperer this man is) has progressed nicely to the stage where the drugs have NO effect at all. It started three years ago after root canal work.

I have just lost a month of my life (and my wife's) because all I thought, ate and did was pain – all day and most of the night between snatched moments of exhausted sleep. If I had been on my own I would have despaired. I can imagine being driven to suicide because there appears to be no possibility of relief. But, because I have a loving wife, I had the support I needed to get through. Don't forget, if you think you have stress, it is shared by your loved ones. They see you in pain and can't do a damn thing about it. They don't sleep because you don't. At least they can eat! The emotional cost to both of us has been horrendous. Now that we have a temporary reprieve (more of which later) all we want to do is

sleep, we are now paying for the weeks of worry and tension.

I am not sure who I am writing this to! (split infinitive – sorry about that) but I guess its to fellow sufferers who might get a small comfort from my experiences but also to the people who look after us.

As far as they are concerned, it has <u>mostly</u> been positive.

On my very first visit, the whole experience was very positive with a genuine effort to help me. Our first visit during this session (this has been going on for a few years now! was met with a blank "we can't see you now, there is an emergency dental service available in the evenings" from the receptionist. Trigeminal neuralgia is not a dental problem! Do not be put off! The level of pain you are suffering requires attention NOW. The hospital staff are no doubt busy, stressed and tired of patients turning up with toothache that their own dentist could fix but…….sit and scream your head off if that's what it takes.

The consultant and staff I have dealt with have clearly wanted to do their best for me. I have been lucky to have these people on my side. My only reservations have been connected with the inevitable fact that no matter how it is impressed upon someone how much this condition hurts, they cannot, no matter how hard they try, really understand the levels of pain you are experiencing. Being told by one of them to go and see your dentist for an injection if the pain gets too bad is not what you want to hear.

Mainly because your dentist doesn't know anything about your condition! (Unless you are really lucky!)

You probably ended up with the specialist after having lost most of your teeth or having root canal work done only to find it was all unnecessary in the first place! My dentist, not the idiot who ruined what little was left of my teeth, is a caring soul but when I asked for said injection, he proceeded to pepper my gums with small jabs until my cheek swelled with liquid! He had no idea what was required. One Marcaine injection in the right place can provide many hours of relief that is so necessary for sanity but it does need training to get it right. His injections, for all their number, only dulled the pain slightly and lasted about one hour. Better than nothing but only just.

In the end though, when I REALLY needed it, the staff at the hospital came through and I got the operation I needed. I have to say though, again it took considerable persistence until the right member of staff was found who could pull the right strings. Once it was realised that I was just about at screaming pitch, one of the surgical staff did the operation on the spot under local anaesthetic.

If it comes to it, and you need something more than pills, there are straight choices. I am talking here about Kings College Hospital in London. As far as Oral Medicine is concerned, CRYO-SURGERY is as high as it gets!! Anything more than

this and you have to get referred to a neurosurgeon.

This Cryo whatsit thing!! It sounded easy enough! “We just freeze the nerve”. “You get about six months relief”. “That’s it”. “Only takes about a half to three quarters of an hour”, “Oh and your face will be numb!”

IT’S A GOOD JOB THEY DIDN’T TELL ME WHAT THEY WERE GOING TO DO!

Don’t let me scare you, seriously, I didn’t feel a thing and the surgeon and nurse were models of caring efficiency. Its just the thought of these things that worry!! But what made me laugh was the casual understatement by the surgeon when he finished that “it may swell a bit” and “you may still get the odd stab afterwards”

The night after the operation I was so engulfed in relief and the lack of noise in my head (its funny but pain is noisy, it roars around and around and leaves no room for anything else) that I sat and had my first proper meal for weeks – warm soup actually – and went to bed happy in the knowledge that the pain was gone and I could eat again. (I had lost 20kg)

At about 2am…….

It all came back. The pain was intense. I took a million pain killers and tried unsuccessfully to get some sleep. The next morning my wife started calling me ‘GERBIL’ The whole of one side of my face was ballooning and a huge yellow bruise was starting to come out.. now all of this might seem reasonable considering the nerves have been attacked but reason doesn’t come into it if it hurts.

The stabs of pain convinced me that the whole thing had been a terrible waste of time. I now had a numb face AND the pain as well! A bit more warning about what is a normal reaction would help!

BUT…….. two days later and hey, it was fading, there was the residual pain that might be expected from the healing processes and the odd stab as I moved what is quite a long piece of cut mouth but…thank god (whoever yours is) its going to be OK. Be assured, it really is. If you have to go through this – it works, the pain (and the memory of it) will go.

You will now have the time to try and sort the problem out long term. Remember this is only for six months (ish) so get to see the neuro-surgeon as soon as possible.

As an aside, naturally, being me, the wound became infected and another painful mini-balloon grew on my face. The wound has now been drained and washed out and I can start the healing process again!! The surgeon reminded me that this is, after all, surgery! It inevitably leads to pain as the body heals – but it will!! Take the time to recouperate properly and take something to make you sleep through

the discomfort. Everything feels far worse when you haven't slept properly for three weeks!!

I am looking forward to my first sirloin steak and a glass of good wine and suddenly the world seems a better place again in spite of the pain. This is not as bad as the TN but I know it won't last.

Of all the experiences I have had throughout this period, the one that stands out is the sight of what looked like a dozen heads, peering into my mouth as my consultant pointed out various things to them. To me, this is probably also one of the most important. If students don't learn their trade like this, people like us don't get our problems solved. Tell them how it feels, where it hurts, if necessary, let them poke around inside your mouth, let them learn. This is the strength of the teaching hospital system. With a bit of luck, a future generation of dentists WILL know about TN and know what to do for their patients.

NOW THEN…. YOU PROBABLY THOUGHT THAT SOUNDS LIKE THE END OF THE STORY!…. so soon ha!

If only life was really so simple! The pain returned. So badly that I might as well not bothered with all the previous treatment. The full surgical team became involved at last, someone listened to me about the pain being located under the sinuses. An x-ray from a different angle showed a shadow where a shadow didn't ought to be so, after the usual shenanigans with getting a bed in the NHS, I now have a much lighter face. They repeated the cryo surgery, removed a large polyp and an old root, gave the sinus a good flush out and just for the heck of it drilled a hole to allow it to drain!!

Has this fixed it? Well no…….. it is possible that its just healing slowly! I still have pain when swallowing – which means the weight I have already lost might not be the last! I get pain when the saliva glands turn on ie when I try to eat anything tasty! I get pain when I try to speak, so I can't work (I sell for a living)

That was two months ago!!

As of now, the 9 months of relief I was promised hasn't started!! I find that my sinuses are permanently blocked which means I have to blow my nose all the time. In addition, I sneeze a lot which doesn't help either.

The nature of the pain has changed though. It seems much more movement based now. So I am stuck with pain when I eat or talk much or try to get a bit enthusiastic when kissing my wife!!

As yet it has to reach the levels it attained previously. I am managing on between 500 and 800mgs of carbamazepine a day. Who knows, it may continue to be

manageable on this amount. Lets look on the bright side. I have had two months of enjoyment of food and drink that I had quite forgotten. Guiness never tasted so good. With the reduction of drugs in my system, everything came alive for the first time in several years. And I very quickly put back the weight I had lost! Lots of puddings and cakes.

But its back and we shall see how bad it gets.

It faded about three months after the operation and apart from a few non painful pulses where there was pain previously. Minimal dose of pills just in case.

Four years on……!!

Cryo is wearing off - giant stabs again. The positive is that it has lasted so long. I was told six months in the beginning, maybe a result of a double operation?

Back to Mr Sh…(neurosurgeon) who is now at Kings. Referred to gamma Knife Centre who apply for NHS funding and get turned down! They tell NHS not to be silly as Cryo already done and Vascular Decompression already offered. Funding approved - await the op!

November 2006 - had Gamma Knife.

Diary kept for specialist as requested- see below:

Dear Mr S…..,

I had Gamma Knife treatment under your care last November. I have kept a diary as suggested and have included it below in case it is of use.

24th Nov 2006
Here we go! Up early. Get to Barts at 7.20 no one else about. Get into MRI at not much before 8. The suggestion was that the worst bit of the day would be the frame fitting. THEY WERE NOT KIDDING! The pain was no problem in spite of the fact that the right rear injection took a while to have any effect (as the screw went in, the pain was quite sharp) but the noise - they didn't warn me about the noise.

If you have ever driven a screw into hardwood with out a pilot hole you may have some idea - a screeching, grinding noise that sets the teeth on edge. The back screws rest on the skull behind the ears, straight bone conduction - nice.
Some sort of warning about this would be a good idea. Felt nauseous when I stood up but it subsided when I got into the scanner. Usual noises off - seemed higher frequency than previous scans.

Trip through to Harley Street strange, probably as I was deaf and blind and the

frame is heavy! Glasses wouldn't fit with the frame on, hearing aids in jacket pocket. Head measured through plastic helmet, surprised only done once with one girl taking notes. I expected that they would swap roles so the readings could be double-checked, maybe this bit is not that important?

Asked for coffee - didn't think about frame!! Had to drink it through a straw!@! Gamma knife was not exciting. 32 minutes seems quite a long time stuck on your back without being able to move your head. I managed to get through Rodrigo and was well into Bacarisse when they pulled me out. Surpisingly, the pinging noise was just about on the beat.

Frame came off with no problems. Spent a while in the waiting room - talking of which! I assume we got the NHS cupboard. In the blurb, it suggested music and films! I guess that's for the paying guests?- felt very tired, eventually needed pills for the discomfort. The front holes are no problem but the backs ones sore.

Specialist tried usual trick of touching my cheek to see what the reaction was, managed to resist flinching but - strangely, there was no response anyway! Decided against overnight stay and went home.
Difficult to sleep as the back holes keep whingeing when I lie on them.

25th Nov 2006
Tired! Sat around most of the day, slept most of the afternoon, slept all night (the night started at about 4pm!)
Back holes still uncomfortable.

26th Nov 2006
Wake up feeling considerable better. One thing though, I have a spreading patch of numbness. Not where it might have been expected on the side of the face but over the top of the skull! Maybe just a short term reaction to the jabs or the pressure of the frame - we shall see.
As far as the neuralgia itself is concerned - quiet! Very small jabs and only occasional at that. Too soon for the Gamma to have affected it maybe but then it does come and go. Perhaps the nasty big machine has scared the little bastard.

29th November 2006
Rear holes still sore - front ones now Ok. Still have numb patch on top of head. The Neuralgia noticeable by its absence!

1st Dec 2006
Still no neuralgia, still a numb patch on the head. Vision is a bit strange today, everything is a bit bright and hard focus. Holes are fading at last.

4th Dec 2006
Still the same, no pain but a numb patch on top of the head!!

8th December 2006
Two weeks on. Holes fading now - numb patch the same- but GUESS WHAT? no neuralgia - not a peep! Not sure I believe this.

23rd Dec 2006
Face- the occasional stab is happening but nothing that I couldn't stand long term. Too soon to know still, if the treatment has worked.

Completed our move to France after three years planning.

2nd Jan 2007
A few stabs today - its the lumps inside the cheek that seem to trigger it.(since learned that the lumps are saliva glands)

10th Jan 2007
Bad pain today - long stuff not stabs

11th Jan 2007
And another

25th Jan 2007
Pain suddenly back to pre cryo levels - just about standable without crying or screaming

26th Jan 2007
French neighbour calls doctor for max allowable dose of Oxcarbezepine - he says 1800mg

27th Jan 2007
In bed - feel disgusting - pills at 1800mg make me feel totally disconnected

28th Jan 2007
Still in bed - pills seem to be holding pain

29th Jan 2007
Phone Mr Sh…'s sec please can we re-consider vascular decompression as its clear the Gamma knife hasn't worked

31st Jan 2007
Mr Sh… calls back. Says that the Gamma tends to aggravate the nerve and we should have been warned about the possibility of increased pain. It also seems I saw the wrong people to start with. If I had gone to the neurosurgical department, they would have dealt with the pain, then talk about treatment, not keep prescribing drugs for ever, he doesn't approve of the levels some people are prescribed long term. Great, after nine years someone tells me that.

Mr Sh… says hang on though. If the pain returns go straight to 2400mg short

term!!! I would need nursing but pain would go. Do not consider surgery at this stage. Wait and see results. Remember the risks.

2nd Feb 2007
Another call from Mr Sh… checking how I am - what a very nice man! It seems he is leaving the NHS as he can no longer stand being controlled by accountants rather than patient need. Another victim.

3rd Feb 2007
Reduce dose to 1500mg as Mr Sh… suggested - make it for a week.

10th Feb 2007
Down to 1200mg top lip now very numb, maybe the radiation is having an effect at last.

13th Apr 2007
Suddenly a small stab!! Why now

17th Apr 2007
Still a small stab a day

28th Apr 2007
Up to 1200 a day again, just a very small pulse this morning before I got up but nothing all day

That's the end of the diary I kept for the doctors, but...

Around the first week in May, the stabs reappeared! Not too bad but a surprise as I had hoped they had gone away for good. On the other hand, if the level stayed the same for ever I could handle it without any problem at all.

Shortly after that, my left cheek, from the top of the eye down to the jaw, started tingling and buzzing. It slowly got worse! Very annoying in fact. What I didn't notice at the time was that scratching the face produced no answering attack. Strange that I didn't notice. However, a couple of weeks on, the tingling has reduced a little and the area is semi-numb.

I have reduced the pills to 600mg a day and sometimes forget one! So far, not even a small stab. Obviously I am not holding my breath as there have been quiet periods before, but as both the cheek and top lip are now numb, it is looking hopeful. Neither is particularly bothering. The lip I am not aware of any more and the cheek will no doubt go the same way (on the assumption that it does end up as numb as the lip)

It seems that at each stage of degeneration of the nerve, there has been an adverse reaction. I am not sure if this is usual and I had no warning of it at the time of the treatment. Mr Sh… however did mention it. Maybe this could be

pointed out as a possibility?

It is six months almost to the day since the treatment and it seems to have taken the entire time for real effect.

It will be interesting to see how things pan out over the next few months. I intend coming off the pills during the next month and we will see.

July 2007.
Back up to 1200mg a day as the stabs have returned. Not as bad as they have been but sharp enough.

So I still have the problem PLUS some adverse effects from the Gamma Knife. I reckon they missed. The tingling reaches over the top of the forehead, up the left cheek, in fact everywhere but along the branch of the nerve you would expect!

November 2007
Yet another Autumn attack. Usual overdose and gradual reduction.

February 2008
Things have been constant. Small stabs most days. One or two more serious stabs and then suddenly worsened to where it hurt to eat or speak.

June 2008
Three months ago, I had a filling fall out and went to see my favourite person in the whole world. Because I have pain if my mouth is open for too long, she just plugged the hole and sent me to see a maxillo-facial specialist.

He took one look at my face and said that my jaw was mis-aligned! An x-ray showed a patch of infection above the root canal work done by the same dentist I was seeing when all this started. His opinion was that dental problems are common but neuralgia is rare!

I have been wearing a brace at night and some times during the day. On the 1st September I removed the brace in the morning and immediately had the most enormous attack with a large pulse and then constant searing pain. 600mg of Oxcarbazepine and 20mg of Urbanyl had a good effect and suddenly the pain stopped dead after about half an hour.
But as always on that level of drugs I felt terrible with spinning head and poor co-ordination. At times since, I have tried to reduce the dose of the drugs but each time the stabs increase. This means, if the present patterns persist, I will only be able to work for about half the year. This means we will soon be on welfare. The business I should be starting in January 2009 will not be possible so I can't make any social contributions so my Carte Vital runs out. If it all continues, we will be destitute and may have to sell our house here and move back to the UK as beggars. The present world financial situation does not exactly help.

October 2008
Dr Gr… (pain specialist) has booked me into hospital for proper observation. She had intended to inject Glycerol to try and damage the nerve (Mr Sh…, the neuro surgeon in England also offered this but I chose to have the Gamma Knife treatment which seemed to offer a more permanent solution) but she has been put off by Dr.Ca…. who is convinced it's a jaw alignment problem, and the Dr Dev…., the neurologist who warns against intervention because of the number of times things have already been tried. His solution is more drugs which gets us straight back to square one.

I am also to see a psychologist. I have tried amitryptilene before which made me feel ill. Yet another drug to confuse my tired old brain?

I feel at a loss. I realise that TN is nigh on incurable but refuse to believe that there isn't a way to reduce its effect without rendering me incapable of clear thought and the ability to work. I already have permanent numbness to my top lip and constant pins and needles to the left side of my cheek and forehead. This kind of effect I can accept, provided my head is clear and I can handle my tools without cutting my fingers off. I am a cabinet maker and guitar maker (Ebeniste and Luthier in France)

During the three months during which I am allowed to start advertising before official registration in January, I have already found a great deal of interest in my work and am preparing quotations. However, all this will be wasted if I am unable to complete or even start the work because of the pain or the effect of the drugs.

I am fully aware of the effect all this all has on my motivation and ability to plan adequately. Starting the business will require a great deal of perseverance and positive outlook. With constant pain and the fear of a major attack firmly in my conscious mind let alone my sub-conscious this is a major problem. The TN takes over one's life. Avoiding the pain becomes the most important thing there is but I know it doesn't pay the mortgage.

I have now seen the neurologist again. He asked me all the questions, went through the usual tests and announced that the problem is definitely neurological and not dental or physical!! He still says that the drugs are the only answer and it's a straight choice between the drugs and the pain. So, apart from suggesting he and Dr.Ca…. do 15 rounds to decide the winner, I have no idea what to think or do. I seem to have the decision to either give up our ideas of living and working in France which means we have to sell the house and waste two years hard work or take a risk AGAINST the wishes of Dr.Dev…. and have the nerve ablated. If this goes wrong I am likely to be left with as much or more pain and it will be permanent and continuous.
Because of the damage to the nerves already caused by the three operations I have already had, there is a greater likelihood of this happening apparently. A sort of phantom limb syndrome.

I have an appointment with another neurologist (or surgeon not sure which) next week to get a second opinion.

My thoughts are that I FEEL that Dr Dev…. is right and Dr Ca…. is wrong. It makes no sense to me, that if the problem is a mechanical one caused by the jaw being twisted, it would not be so periodic or show so many other typically neurological symptoms, but react every time I move my mouth to eat or speak. I have been eating only on the right for nine years to try and avoid the pain and so the problem with the jaw is a result of the pain and not the cause.

So after three days in hospital for 'observation' it seems I am no further on and in fact I feel as if the whole thing was a waste of time.

The dental treatment under general anaesthetic hasn't happened and I didn't get to see the psychiatrist. Its cost around 4000 euros to my Carte Vital and the Swiss Life which should please everybody!

The food was good though.

Watch this space.

But not for long……

November 2008.

Pain progressively worse. So much so that I could no longer eat. Ronnie called ambulance!! Blue lights and noisy sirens fascinate neighbourhood.

Get to hospital. NO-ONE HERE who can give me the injection I need. Please take these Morphine pills and GO HOME.

Next day, doctor is a bit upset. I am straight back to hospital, on a drip and morphine, in pain and more that a little confused. When I get out I wrote the following email to a friend.

Ah.... the memories, the images from the past that create such feelings of comfort, feet warm as toast in front of the fire and the wonderful, snuggly, Sunday morning feelings that only in England's (or if you must, Wales') fair.....

well, sunshine, you can forget all that wishy washy crap and get real. This is real life. At PRECISELY 6am, there will be a clanking of trolleys, the lights will go on and a large French matron will shove a cold (gasp) piece of plastic in your arm pit and god help you if you let it slip or ten minutes later she will rush back in and replace it even more forcefully than before, not necessarily in the same place.

Five minutes later, your body system will realise that it is the next day and that the drugs they gave you yesterday will have to ceased to have any effect at all hours ago because the whole hospital system shuts down at 20.00 hours whatever your problem. So, 'scuse me guv' say all nerve endings - in unison - or in 5 part harmony whatever, er 'I hurt'. Quite a lot actually. In fact so much that, if I wasn't a properly trained Englishman rather that one of those namby pamby continental wallahs, I would be leaping up and down screaming to whatever god it was I believe in this week and asking why he had forsaken me.

So you press the red button. The nurse - lovely, caring soul, in stiff white linen and neat little cap and lacy garters just showing..... sorry about that.....pops in and says 'ca va?' To which I say absolutely nothing but point at face and mouth 'douleur' with a rather pained expression on the side of the face that I can move.

'Ah', says she, and pops off to find a suitable potion. When said potion arrives, it hurts so much to actually swallow the stuff that at least I lose ten minutes conciousness of the 30 minutes it takes to have any effect.

In the meantime, breakfast arrives. So, I sit and stare at the rapidly cooling bowl of black .. er... coffee (hey, is this France – its rubbish) nice CRISP bread roll - you know, especially designed to be easy on gums and mouth in general. About 20 minutes later, the MOST friendly member of staff pops in (great big black woman with a smile the size of the channel tunnel and a heart probably as capacious as her body is wide). edges sideways through door, looks at my untouched breakfast, tut tuts, grabs it all up and wends her way with what by now I could probably just about have managed to imbibe - slowly.

Not boring you I hope.... anyway...

About 10am, Lancelot Spratt sails in with usual retinue (funny, also all female in nice stiff white...) asks if it hurts, says stand up close eyes, picks me up off floor, makes notes, signal to nurse that reads 'MORPHINE' in whatever language you choose and sweeps out. Ten minutes later, world slowly recedes into warmish glow that somehow allows pain through. Meals arrive and get stared at, tut tutted and removed just as courage plucked up and then its 20.00 and a .....

.....quick Deja Vu situation seems to arrive.

Occasionally, an angel arrives to check me out but then she has to fly off to check her chickens, translate a couple of redundant cockerels (all named Patch) to heaven and make sure the cat is peeing properly against some part of the carefully restored part of the house.

Am aware occasionally of a fog horn going off just outside of the window which, in retrospect, seems puzzling, as the hospital is quite way inland, and the local gravel pit is unlikely to house anything bigger that a surfboard. Turns out it me! Snoring - you don't have ANY idea - and nor does Ann - what the expression

means. In their wisdom, one of the drugs the Drs are trying is one that should never, it says on the bottle (that reads N E V E R in any circumstances on pain of a smack from the nurse in the stiff white.....) be used where breathing may be a problem - you know, when under the effect of Morphine, that sort of thing. The noise is me taking one HUGE noisy breath after not breathing for the last two minutes. Fortunately, lack of oxygen to the brain never has seemed a major problem in my case so no harm done there....

So... what has been achieved? I am alive. Which is good. I hadn't eaten or drunk anything for three days before coming to hospital so keeping me hydrated was quite important. I am back in control of my own pain which means I wake up with just enough in the tank to allow a top up so that the pain is low enough to actually EAT breakfast. (there will always be times when the whole system collapses and I can't cope but that's the same at home or in hospital)

I am down to 66.5kgs. Lots of opportunity here for that sad look at Ronnie and the poor brave attempt at brightening features when the magic words 'spotted dick' or 'almost any other pudding you can think of' are mentioned. I can make this last for months.....and Christmas is coming, I think we have one left from last year's batch!

There has been a realisation that DRUGS ALONE might - oh god - how can I say this? - might not be quite enough and a surgeon might need to be called in. Now this is strange, as over the last nine years, this VERY SAME conclusion has been reached by every other specialist I have dealt with. This is why I have already had two attempts to fix it surgically. The doctors here have, in fact, been informed of this. It's a tough one to fix unfortunately but then we know its 'incurable'. There just has to be a 'work around' found or we all give up and I retire to the wheelchair and the Sherlock Holmes medical kit.

Our local GP got the French 'experts' involved in September 2007. But their own opinions instead of the reality of the situation allowed things to continue for a year longer than necessary. During that time, the illness has progressed nicely and is obviously worse than it has ever been with the urgency increasing by the day. Why is it that professional pride won't allow some people to admit they have reached the limits of their knowledge and be willing to pass the baton up the line? There are ALWAYS, yes, even for me, people who are better, smarter, more qualified etc. I would have thought that in something like medicine, this thought would be a basic and continuing part of training. Our GP has done his job and been very supportive but is, understandably, a bit defensive when I suggest I'm a bit upset about the lost year and assures me that they are all trying their best to help etc etc. I quite understand his situation. However, he now accepts that its a surgeon is what we want, that we know the risks and that is what is going to happen. It's just a matter of when.

What they seem to forget that with a long term problem like this, the customer spends more time in research than they do and could well be more up to date. I

know all the problems, treatments, operations, drugs, risks, death rates all that stuff. I have files of the stuff, internet searches, you name it. They also need to accept that patients have a certain rapport with their own bodies. I can feel what is happening, the nature and level of the pain, what movements affect the pain. All this tells me of the progression and how far away a major blow up is. WE knew for a certainty that if it hadn't been last week, it would have been this. The body knew it was coming. THEY have to accept that there are sometimes more that just classic clinical indications.

The rest was personal stuff.

Apparently one day when Ronnie (my wife) came in to see me she thought I was dead! I wasn't breathing. She had to shake me before I took a proper breath. This is worrying stuff quite apart from how she must have felt.

So, another neurologist next week, this time in Bordeaux (working our way up the ladder) so that I can tell her I don't want any more druggy solutions and bring on the executioner.

Thank god.

Someone who knows what she is talking about. Actually wants to find the real reason behind the problem before deciding on therapy. Also take it SERIOUSLY. Realises the urgency and has arranged for things to happen quickly. Hope at last.

The Rivotril that Dr Dev…. prescribed has had some unexpected side effects.

1. It doesn't work
2. Upsets my stomach
3. Makes me more and more depressed. In fact I reached the stage I just wanted to go to bed and stay there. There was no hope so why bother.

Reducing the dose – have to get off this poison. Have increased the Oxcarbazine to 1500 or 1800mg per day. Just as 'effective' pain wise and I feel better.

After two days down to 4 drops per day. I feel human again and Ronnie says she has just got her husband back after he was missing for three weeks!

Still getting stabs but Local Anaesthetic is helping reduce the pain so that I can eat. Why is this?? If it's a primary problem why does it work. My feeling is still that it is all in the nose/facial area. We shall see. Why can't they use the Gamma Knife machine to damage the nerves in the cheek instead of at the ganglion? Presumably this would be more permanent than the Cryo surgery?

19 Dec 08

So, we have an appointment to see a dental person just before Christmas. Get there. Told to sit in the chair and open wide. She takes a mould of my mouth. No explanation. This hurts! Go away…….

23 Dec 08
A few days later, we return and are given a plastic mould with two wires hanging out. No explanation. The pain clinic is closed we are told. We have just come all the way from Angouleme to be told this. Go to clinic anyway and fortunately the nurse is there who explains that I am to have a TENS machine (Transcutaneous Electronic Nerve Stimulator)

This appears to work as I have no pain at all for two months. I feel human again for the first time for ages. Eating normally, smile on face and able to do all the things that we should be able to take for granted.

In the meantime, Dr Dou…. (pain specialist) has asked for an MRI scan to be done. Angouleme manage to fit me in first. When it is done, the doctor says he will send the results to Bordeaux. We have an appointment to see if it's worth removing the canine which has infection above it still (didn't Dr Cal… operate to fix this?) Get there. No scan!!!! Make another appointment. No-one seems aware that it costs us 100euros every time we go to Bordeaux.

Visit Angouleme and they have sent it to our GP who is on holiday!!! WHY? He didn't ask for the scan.

7th March 09 – A sudden nasty attack – very sharp, pulsing and continuous. Oxcarb, Urbanyl and generous amounts of local anaesthetic manage to control it. Big shock after all this time. The problem is that one tends to forget the intensity of the pain.

Nervous to eat again but manage some scrambled eggs and strangely, apple crumble (almost nothing stops me eating apple crumble)

This is very bad timing, We have started the business, have jobs in the pipeline and need to make money to pay our social charges or there will be no health cover. This is not possible in my situation.

Monitor the next few days. Dr C…. back on Monday. If pain increases will ask for emergency appointment in Bordeaux.

In the meantime, go to see Maxillo Facial specialist in Bordeaux, who says she can see nothing on the scan that indicated we should do any work beside the nose. Great. Go home.

Go back to Bordeaux to see Neurosurgeon. Takes one look at scan and said it was no good. Now there's a surprise. Go home and call in on my best friends – Angouleme Hospital. It should have been good enough whinge whinge. Book another.

In meantime pain still building. Email Dr D…… to ask her if there is anything she can do. Apparently there is. I got home from a job for my wife to tell me Oh by the way, you are in Bordeaux for a couple of days for monitoring and get a proper scan done. Ye gods.

The two days turned into seven as recounted in an email, this time to my nephew.

So Moriati,

You thought I was gone for good huh? Not as easy as that my friend. Bloody close though.

I thought I was going into hospital for a couple of days observation and to get a high res MRI done. Another cunning plan goes west.

Let me tell you about Professor C….
Some people say he learnt surgery on his father's knee (Dad managed quite well ta very much. Three legs have their advantages especially this one as it musical. I wonder if this is why all three legged things have been called triPods since!)
Some people say he's an alien sent show us all how slow and stupid we are.
Some people say he's GOD
I don't know about that but I know we call him..... er bowing slightly.....Professor C….

His French moves through hyper-space, his English has to make do with sub light speed though, as he probably has to think about adding that wonderful French accent we all love so much.

When you meet him there is a sort of increased pressure in the air, you look up and there he is. He speaks in a sort of - me god - you mud - I decide and it will happen - way. You start to bow, slight decrease in air pressure and he's gone. Lancelot Spratt is Uriah Heap to this one.

There is however one problem. His hands. When Ronnie and I were first allowed a short amount of his time - if Gods actually do time - we both stared at his hands. Afterwards I said to her and said that if anyone was going to drill a hole in my head with his Black and Decker and then delve around inside separating all the nerves, blood vessels etc, trying to get a piece of Teflon between a blood vessel and a 3mm long piece of nerve channel about 5 centimetres inside the skull without damaging any other functions, these are the hands. They are attached to Professor C. Beautiful long slim and elegant fingers of incredible length. Exceptionally clean and well manicured. The sort you see in Renaissance paintings. Perhaps he was there too making musical shins.

So I had the scan. Worst kind of atonal French crap music you can imagine. It ain't got no rhythm. Anyway, afterwards, lay on bed studying the way the French put false ceilings in and whoof..... there he is. "I have looked at the scan - you need the big one - I operate at 8.30 tomorrow morning (sadly, although this for me is a routine operation, it still takes me three of your earth hours)- you will probably have a headache afterwards". Whoof.

***I think though, that I have been very fortunate to have this man as my surgeon**.*

Few problems here as always. No drugs after mid-day meal. So as time drags by with me wondering why my normally sort of well, at least half quick brain failed spot any movement before or after his arrival, the inevitable happens. The drugs start to lose their already weak defense against this disease. By 1am, bang. Full power. Foot hard down. I think it must have deteriorated considerably since the last time I went through all this. If I hadn't known that in just a few hours those hands were going to weave their magic, I would reached for the two packs of morphine I had secreted in my laptop bag. I now REALLY know why this is often called the suicide disease. The strange thing is that like the Brits, they offered me paracetamol. Unfortunately, I can't attest to the quality of their anticedents in French as well as in English, so it took some time to persuade them it was morphine that did it for me. Each one lasted a couple of hours. They jealously dolled them out one at a time. Eventually morning came.

I woke up. I couldn't breathe. Brain sensibly said "sod that" and switched off. Woke again. Still no breath would enter. Brain stayed connected - damn. Tried breathing with mouth. Aha, a flow. A shadowy figure appeared, sprayed my throat with something and pulled a long black something out of my throat and nose now worked too. I suspect this meant I had lived through it all.

I could go on but who needs any more details of a so far successful operation. Time will tell.

"probably have a headache afterwards" Hooray - gods have a sense of humour. Guess what - paracetamol doesn't work on them either. Who would have thought. Never mind - still have something in the lap-top bag.

G

I suspect there may be a lesson in here somewhere. Not that I am teaching it of course. I am far too modest to propose such a thing.

This thing has effectively run my life for nine years and it is only now I can see what went wrong.

The first thing is that this is YOUR problem. Whilst the doctors who give us such care have the knowledge, you owe it to yourself to gain as much knowledge as

you can as well. One question of your doctor could change the direction of the treatment. Know all about the available treatments.

Also no-one but you knows how much it hurts. If it's intolerable for you then it is. Full stop.

Make sure you see the right people. I was hopelessly misguided. Dental problem it is NOT. Once it is diagnosed you insist that you want to see a neurologist. You need to get this fixed as soon as possible.

Be insistent, even rude but get it done NOW.

Be brave. I have spent the last few years being frightened of the operation that, so far, has removed the pain entirely. If a scan shows that you need MVD have it done. Five years ago there was still a great deal of fear over the possible unwanted effects of this operation (death being one of the more serious) but medical science moves at a huge speed and this sort of thing more and more routine to our better surgeons. All the 'safe' option of the Gamma Knife did for me was give me extensive nerve damage which cannot be reversed and which I have for life.
It is though, as nothing compared with the pain of TN.

Half measures and temporary fixes mean that it will definitely come back. My fear of the pain stopped me getting on with life just as much as the pain itself.

So GET IT FIXED!

So, where was I? Ah yes.

Got home, felt absolutely manic for two days. Relief or what I am not sure. Anyway I soon slowed down.

MVD day was 2nd April
My birthday 3rd April
MVD +14 days. Still no neuralgia. Ear is a problem, air leakage when blowing my nose. Sore at the top. The whole area around the site of the operation is still sore.
Spent the whole day in front if the fire snoozing. Absolutely no energy at all. Salt tablets are making me feel nauseous.
Blood test this morning will hopefully show that I don't need to go on taking salt pills at this level. I am taking at least three times the maximum recommended dose.

MVD+15 days. Ear completely dead. Back of head around 'the hole' still very sore

MVD+16 days. Ear cleared!! Blew a bit hard and the ear popped. Felt better after

poor night's sleep. Did some work to the chicken house. Blood test arrived – so quick. Salt levels are normal!! If I continued at 6 huge tablets a day, I would have toxic shock or something equally 'orrible.

MVD+20 days. Back to proper work – well a short working day anyway. Felt tired a bit quickly! Still fine otherwise. Scar is gradually becoming less sore.

4th May 2009
One month and two days on.

I see God. On the road to Bordeaux. Actually at the end of the line to Bordeaux.

Professor Cuny wasn't feeling well. He smiled a lot. And said nice things. Like 'You're cured'. I liked that bit.

He said that if the MVD was going to fail it would be in the first two weeks. As I had managed a month and there was an instant cessation of the pain, as far as he is concerned, there is no reason why the fix shouldn't be permanent. This was in his experience of the operations that HE has done.

He as impressed how quickly I had recovered – for a man of my age!

The other symptoms, like the hearing, the pins and needles and the problem beside the nose are probably the result of previous attempts to fix the problem and not related to the MDV.

Sounds good to me.

There is nothing I have to be careful of, I can sky-dive tomorrow if I wish or go motor racing – no problems.

What a very nice man.

What am I saying? Man?

This may be the last entry……..I live in hope.