

To Lisa and Lauren

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Introduction

This paper serves to document my experiences following the diagnosis of a cancerous brain tumour, a Glioblastoma Multiforme Grade 4, a High Grade Glioma, in August 2005

It is the third edition of a publication that first came out in July 2008 (Survive and Thrive - my encounter with cancer"). The second edition took my longevity to the positive feedback on my November 2009 MRI Scan, adding the suffix of "cont." to the title. Now more than 8 years post op, this latest edition brings events bang up to date going 100 months post op on 28 December 2013. As such a further amendment to the title is appropriate. Back in September 2005, the title of Survive and Thrive represented the objective. Now more than 8 years on, it would be fair to say that I am surviving and my family and I are most certainly thriving hence the amendment to the tense of the title.

Whilst lacking the drama of earlier editions, some 100 months on since that August Bank Holiday op, shows just what can be achieved. The original comments have not changed although recently I uncovered an error. Previously I'd talked of a 3 1/2 operation. However, I've found I did not emerge until 3.00p.m. Some of that time was in the High Dependency unit, but my wife was left fearing the worst for 7 hours.

As well as making this correction I have taken the opportunity to add a small amount of additional material although this is apparent in the *text*. Importantly, my original comments have not changed, thereby maintaining the honesty and integrity of a diary. Up to my discharge from Kings College Hospital comments are written from memory or after conversations with friends and relatives. Post discharge the comments are from notes taken at or immediately after each meeting. This was the world a man with a hole cut in the side of his head saw, so cut him a bit of slack.

For those looking for a well-crafted novel, look elsewhere. This is a simple log of events as a patient went through his cancer journey, written as he went along to help him keep a grip on things. If one other person can get benefit from reading this, it will have exceeded its original aim.

As I am still here, this is a story without an ending. At this stage can I say thank you to all that have taken me this far.

Feel free to contact me on davidgrant.mapm@yahoo.co.uk. In the words of the song "just believe in yourself and you will do tremendous". To be continued...

David Grant
December 2013

Background

I'm sitting in my Belfast office and have a headache. It's distracting rather than painful but I have a lengthy meeting later in the day and want to be on top form. I pop across to Boots and spend 16p on a packet of Paracetomal. I take two, which sorts me for the meeting.

I've been feeling increasingly tired but I've been working hard and I'm just 2 1/2 weeks away from 3 weeks leave at my house in SW France, that'll sort the tiredness - I think.

Back home in London I find I need to sit up in bed two nights running to relieve a headache. Something that hitherto, I've never been troubled with.

At the weekend, Stephen and Sian come round for a barbecue. I don't feel quite right and in the early hours of Sunday morning I'm vomiting. I put this down to a virus I've picked up from Lauren, our 2 year old daughter. I'm not well enough to go to work next day but something is telling me to get an appointment with my GP, rather than just sit it out. I see his nurse, "try a dairy free diet for 24 hours". If I'm not better in that time, come back and she will get me into the doctor.

A day later and I'm no better, worse in fact. I return to the surgery with Lisa, my wife. I have little recollection of this visit but understand I was incoherent with my arm twitching badly. Dr Patel swiftly gets me admitted to St Mary's, Sidcup. Lisa takes me over in her Mini Cooper but on the way, is unable to prevent me from ringing the office and barking out some incoherent instructions.

A scan reveals a possible tumour. Having referred the results to King's College Hospital, Saturday morning see's me dispatched by Ambulance with the blue lights and siren on, over to King's. I'm making a bit of a recovery and quite enjoy the speedy journey around the crowded South Circular.

The Operation

Kings College Hospital (27.08 - 01.09.2005) (E092 on my wristband)

A friendly welcome and I'm put at my ease although by now I can feel I'm going down hill rapidly. The operation is set for 8.00am next day. Unknown to me, Lisa is counselled that I may not come out of the operating theatre as the operation carries a high risk of a brain hemorrhage. Next morning, my brother in law Richard, and his wife Nomita arrive. They stay with Lisa throughout the operation. Richard is always late for family gatherings, but he came good today, when it mattered. I'll be forever grateful.

I've regained consciousness and seem to be in a holding area. I later find out this is the High Dependency Unit. It's a little dark but I think other patients are in the vicinity. There are monitors either side of me. One has a steady bleep; the other is going like a pinball machine. I ask if both monitors are mine. It's just the steady bleep one that's mine and I'm doing very well. "So less beeps is good", I unhelpfully say, forgetting the demoralising effect this could have on the other patient. I allow myself a little grin. The expectation is that I will need to be in this unit all day but I'm in good enough shape to be out within 30 minutes.

Later I hear from Lisa that the problem with most patients is getting them to talk. Lisa tells me they have a different problem with me - getting me to stop! Apparently I was making wisecracks whilst being wheeled out post op and the nurse was getting annoyed with me! "This is serious," he was saying. Sorry, I was just trying to get back to my usual self.

Back in a ward, they are clearly very pleased with the operation. A tumour the size of a walnut was removed - everything they could see. My limbs are all working with equal strength (not much) and spots before my eyes and seeing double are indeed, as predicted, temporary things, correcting themselves in a few hours - the patient opposite did not in fact have twin brothers that married twin sisters with a liking for lurid green tops!

Throughout the day I'm asked if I know what day it is, where am I and who is the Prime Minister? I'm swiftly recovering and tell them that George Bush is in charge when it comes to foreign affairs but he lets Tony Blair deal with the minor domestic matters. "I like Tony Blair" protests Stuart, an excellent nurse from Perth, who motivates and encourages me throughout my stay at King's. "We have a problem but its not medical" I hear another say. Whilst not necessarily agreeing with me, they are encouraged by my alertness, if not my wit! Much later I find that humour is an important part of brain recovery - it doesn't have to be a good joke, an attempt will do.

I'm clearly going to need care in order to make a full recovery but what I want to know is what I can do to aid my recovery or if it's cancer, what can I do that will make things hostile for the cancer, no matter how small? At this stage I have not been told that it's cancer although I'm sensing a change of mood. I'm thinking that 40 years ago we were still a year away from the first heart transplant, yet now these are common place and they're telling me it's a less complex op than the one I've just been through. I ask what

I can do to help myself. A nurse tells me to take plenty of fresh fruit, cook only with olive oil, don't take caffeine and drink a glass of red wine a day. Deleting Caffeine from my diet is the only improvement I can make, but every small step helps. As an experienced project manager I lecture them on the beneficial cumulative effect of many small changes.

My memory of these early days is a little hazy but I remember complaining to Stuart about some incidence of negative behavior. "I'm going to fight this", I rant. "Of course you are. You've got Highland blood in you" he replies. Another tells me that I'm not like their usual patients –I think that was good! Whilst images of my darkness hours attempts to swap over my full urine flask remain vivid!

I'm performing well. On Monday I'm out of bed but being helped to the loo. Whilst Tuesday see's me escort Lisa back to the ward entrance – much to her surprise.

Monday sees the start of visits. Lisa brings in our daughter Lauren, just 2 1/2. A lovely smile but clearly unsettled by the past few days. We agree that to minimise change on her, she will stay away from Kings. I will next see her either when I get a transfer to Sidcup or home. Monday afternoon sees Stephen and Sian call. I must look a state from our last get together a week ago. Lisa is in every day whilst Wednesday brings Andy with some reading material and in the evening, Ray and Sandra with a little bottle of wine - can't beat a glass of a health drink. Ray tells me that my voice sounds more Scottish. Nothing the matter in that.

The intention had been to keep me at King's for a few days and then transfer me back to St Mary's, Sidcup to be nearer home. However, such is the pace of my recovery that talk swiftly changes to a discharge date to go home. There is talk of Tuesday but a doctor is nervous at the swelling under my left eye and wants a further 24 hours to keep an eye on it. I'm not worried. I knew the swelling had peaked and was on its way down before he saw it. I'm happy to endorse his conservative approach. I'm theirs for as long as they feel they can usefully do something.

It was looking like a Wednesday discharge date but Rachel Macarthur, (Neuro-Oncology Clinical nurse specialist), wants to keep me in until Friday so they can make sure everything is ready. Drugs will need to be dispatched from the Pharmacy and this is often a slow process. *Later on in my treatment at St Thomas's I find the delivery of drugs to wards is a consistent failure point, wasting nurses' precious time. I assume they are following a standard NHS process. A review of the process seems appropriate.*

By Wednesday I'm really thinking I should have challenged this Friday discharge date.

Friday is also the date for my meeting with Rachel to find out about the analysis of the tumour. Unknown to me at the time, Lisa has been tipped off that it's almost certainly cancerous. Indeed, having been warned that I may not be coming out of the operating theatre, when I do, and upon asking, is counseled that I've got 12 -15 months. She keeps this to herself until 2008. Darling, I'm so sorry to have put you through such an ordeal.

On Wednesday morning, I'm transferred to a single room. My old bed is needed for a patient with greater needs. Whilst I'm happy with the privacy, construction work outside prevents me from getting any peace during the day, and at night; the area seems to be used by the gangs of Camberwell to conduct their noisy business (it sounds like two gangs betting on dogs fighting).

Other than the occasional nurse looking in to see if I'm still there, nothing is done with me during the day and my move has not been notified to the meals service, eventually I get food. A cantankerous Irish nurse is on duty. I remember her aggressive stance from my stay in the High Dependency Unit. She is a bully and her attitude to her colleagues is appalling. There may be treatments that call for such a confrontational approach, but it seems an unsuitable approach for someone that's just had a hole cut in the side of his head.

Next day another patient tells me that last night was chaos. The two nurses on duty simply could not cope - one patient tried to commit suicide, ripping out the many tubes going into him. In the end he had to be tied to the bed. I reckon this was the one in the bed next to me on Sunday that was screaming "I want to die" as I was responding with a mutter of "I'm going to live" It was nearly midnight before he got his drugs. I got mine at 10.15 pm from the angry Irish nurse (she is a disgrace) but that was only after I checked they knew I was there.

Keeping me in on Wednesday was a mistake. I lost sleep and the comfort of being with my family, whilst the hospital lost out by the simple presence of a patient necessitating the administering of drugs (which could have been done at home), feeding, bed changing, looking in to check etc.

I'm able to get a Thursday discharge and Lisa picks me up in the Mini. The drive around the south circular is quite pleasurable after the last few days. Waiting for me is my little daughter with a big smile but clearly unsettled by the last few days. My other brother in law, James, is also there and that evening cooks an excellent Chili Con Carne. A mild one, no point allowing a dash of Tabasco unsettle the work of skilled surgeons. The meal is followed by a good night's sleep in the comfort of my own bed, back with my wife. It's good to be home.

Analysis and Preparation

02.09.2005 — Analysis of the tumour results

Back to Kings College with Lisa to see Rachel MacArthur, an oncology nurse, and hear the results of the analysis of the tumour. Rachel is to be my primary contact if I have any problems. A male colleague joins us but he plays no part in the conversation.

Whilst the operation was successful in that the tumour was removed, as anticipated, analysis shows it to have been cancerous. Although the tumour was removed in its entirety, cancerous cells will remain and in time will re-form into another tumour. She tells me there is some good news in that this sort of cancer does not spread to other parts of the body. I'm unsure how good this news is - impacting the brain seems a pretty big bit and seeing my ability to donate organs undiminished is of little comfort.

I will need to undertake a course of treatment. The standard is for a single 6 week course of Radiotherapy with daily trips to St Thomas's. I'll need a mask of my face made. It's a bit swollen at the moment but it's on its way down and in any case, adjustments can be made.

Bad news is that Radiotherapy alone only postpones the problem for a year. So I've only got 12 months. OK what's the work around? I'm back to thinking as a project manager, Project Grant Comeback begins. Apparently encouraging results have been obtained from a concurrent application of a Chemotherapy drug called Temozolomide (Temodal is the brand name) but there is little funding for it and unlikely for my postcode. Do I have private healthcare? Yes I do. Ah, that's different.

After Rachel leaves the room I call the Royal Bank of Scotland Healthcare team at Norwich Union. They confirm funding for the Chemotherapy and, even though I didn't ask, the Radiotherapy. Apparently, Dr Beaney is on their list of consultants that charge reasonable rates. I tell Norwich Union of the hospital insisting their commitment is put in writing by the time of our next meeting. This will be done, but they are annoyed that the NHS is putting me under this pressure. "If they have a problem, tell them to ring us. They know who to call". All in all, Norwich Union are excellent, providing the cover, but at the same time, reassuring me and putting me at my ease. Not all customer service centers are the same. Next day I e-mail Rachel the "sanction".

Rachel had told me I'll be put up for everything. Presently they are doing work on food supplements. Kings are at the forefront of cancer research but when I ask what I can do to help myself, she counsels me against quack solutions. She has researched 500,000 cancer web sites and there is a lot of nonsense out there. As for "Super foods", there is no scientific evidence to support their claims. I tell her that nobody is going to make money out of my misfortune but that I'm up to join in any legitimate experiments. I mention my BUPA health check back in June. I was doing more than pass, I was hitting the "ideal" range for many categories. My message is, put me up for the experiments. My results will not be distorted by failures elsewhere in the body - I'm otherwise very fit! It's a theme I return to throughout my treatment.

By midway of the treatment I'm likely to need assistance in getting to the hospital. She warns me of the likely hair loss during treatment and strongly advises wearing a hat when outside in the sun. At the end of the treatment, I'm not to be alarmed if, 4-6 weeks later, there is a blip in symptoms. This is the brain just trying to get back to normal. *Post treatment note - I never did see a blip in symptoms and aside from day 2, I made it under my own steam.*

This has not been a great meeting. The news is bad but the absence of encouragement to survive is both disappointing and surprising. I will not accept the "inevitability" and will fight.

We travel home to break the news to Lisa's parents, who've been looking after Lauren. On the way we discuss my survival strategy. Central to this is that we must not let this scar the childhood of Lauren, our lovely daughter. Everyone says how like she is to my mother, herself tragically passing away just a few months ago. Sadly, my mother lost her father when she was just 10. I must therefore survive until at least 2014 when Lauren will be 11. Getting to that date will mean that I will have been able to provide for my Daughter a year longer than my Grandfather was able to do for his. The stats are against me but stuff them!

In the evening, I call cousin Val in Inverness. "You've got your fathers steel" she says. Thanks Val, I hope so. It's this sort of fighting talk that drives me.

That weekend, when the three of us are together, it would have needed a detective to spot anything amiss.

On an immediate practical level we decide to put the house up for sale and move to Tunbridge Wells to be nearer Lisa's family and friends. We were starting to think about moving to pastures new. My setback just accelerates the timetable and dictates the destination but as a friend said, "Tunbridge Wells is not a bad place to be forced to live in". I know, I just wanted it to be our decision, unencumbered by other factors.

It's that weekend I start this Treatment Log: "Survive & Thrive - my encounter with Cancer". It's not the snappiest of titles but it's descriptive and sums up my approach. It's deliberately worded in the future tense as I will survive and having done so, I, and my family will thrive. I'm going nowhere. The Grim Reaper will have to wait.

05.09.2005 — a bit of memory loss

I put my card into the Cash Dispenser and find my recall of the PIN number is wrong. On being readvised of the number, I find I had the correct numbers, just in the wrong order. Get a grip Dave.

06.09.2005 - To my GP

I call on Dr Fish, my GP, to apprise him of the situation, obtain a prescription and get signed off from work.

He had not heard from either St Mary's or Kings College and is shocked by my news. I'd had a brain scan 2 years previously and there was no indication of a tumour. To have gone from nothing to something the size of a walnut in that time is "desperately

unlucky”. He commends my decision to keep a diary saying that things will get complicated. I ask if he could sign me off for the rest of the year. I’m almost embarrassed to ask for such a long time off. I’m sure I won’t need it. “You’ll need a lot longer than that” he retorts and hands me a certificate for 6 months. Bargain! There is no way I’m going to be sick for 6 months. Or so I thought at the time! He tells me to call on him every 6 weeks or more often if ever I feel the need. There is no bigger operation than the one I’ve just been through he says.

Later that morning I see his nurse to get the stitches removed. It turns out they are not stitches but staples - 24 of them. Apparently staples are better in that they do not leave a mark, but cosmetics are the least of my problems! She is surprised King’s released me without removing the plasters covering the wound, but removes them with minimal discomfort. I wish all nurses were as good as her. I’m given the staples as a macabre souvenir.

I leave the surgery in optimistic mood. It’s good to deal with professionals and I know I will need to lean on Dr Fish in the months/years ahead.

08.09.2005 - St Thomas’s (Hospital ID 427665ID)

I’m scheduled to see Dr R P Beaney, Senior Consultant, but he calls shortly before I leave to say there is an internal meeting he must attend but one of his team will see me. He apologises as he knows I “must have taken a day off work for this meeting”. I’m taken aback by this comment. Did he really expect me back at work within a fortnight of a brain tumour being removed?

I meet Rachel MacArthur together with Dr Teresa Guerra. The mood is very downbeat. Rachel acknowledges receipt of my email, commenting that my private healthcare is covering the cost of the Radiotherapy aspect of the 6 week course as well as the Chemotherapy. This will make things a lot easier for the Finance Department she tells me. Sounds a disciplined bunch.

Dr Guerra outlines the content of the treatment. She describes it as an application of Radical radiotherapy and chemotherapy. After the conclusion of the course they will give me a break of a few weeks to recover before starting on an increased dosage of chemotherapy. She describes the potential side effects and I sign a patient consent form for the Radiotherapy. Under “Intended Benefits” she lists 2:

1. Prolonged Survival
2. “No Cure”

The second “benefit” sums up the mood I’ve encountered since being discharged from Kings. Everyone knows there is currently no cure for cancer or the common cold, but to have this rammed at you, flies in the face of other advice of staying positive. I hardly think that not having a solution is a benefit and growl that “in the world I come from, not having a solution is not good. It is not a benefit”. This episode sums up the atmosphere of moving from “Cure” to “Care”. I’m not interested in care, what can we do about a cure? This is not going to be about the management of decline.

I’m mindful that 40 years ago we were still a couple of years away from the first heart transplant, yet now, this operation is regarded as less complex than the one I’ve just been through. Later that afternoon, a look on the Internet reveals that the U.K.’s first truly successful heart transplant was not done until 1979, ramming home the pace of

medical development. Now what can you do about Cancer?

I'm warned that by about half way through the treatment I'm likely to need escorting to the hospital. Conversely, I'm encouraged to exercise as without exercise I'll find that one of the drugs has a wasting effect on my thigh muscles. I think it was the steroid Dexamethasone but I'm not sure.

I move to the Mould room where Julian Chapman has concerns that my face is too swollen to make a mould. I point out that I had raised this point with Rachel MacArthur on 02.09.2005 and understood that minor modifications could be made at the final fitting. I sense his objections are because he is behind schedule. Whilst I was told of this appointment on 02.09.2005 (confirmed in writing), it's clear he only found out much later. None-the-less, construction of the mask goes ahead.

Although, my search on the Internet was comforting in seeing the pace heart problems had been overcome, it was not all good news. Rachel, I know you warned me not to look at the Internet but I've just found the web site of the manufacturer of that drug you were telling me about (Temozolomide). It's boasting very encouraging results. As you said, Radiotherapy is only good for around a year. This drug company (Schering Plough) seems to agree with you, quoting an average survival of 14.2 months. However, with a concurrent application of this Temozolomide drug I'm going to have, a control group of almost 600 patients saw this average soar to 18.3 months! Now, in any other business a 29% increase in performance would merit top rewards at bonus time. However, in human terms 4.1 months gives me an exit date around a fortnight after little Laurens 4th birthday and a fortnight before Lisa's 40th. Not great timing. I will not let that happen.

16.09.2005 - A break in France

In an attempt to salvage our summer holiday, Lisa snatches a break in appointments and drives us all to our place in South West France. It's fantastic to get away but I'm angered that this cancer is interrupting my every thought and plan. I must sort out a solution.

19.09.2005

I'm back at St Thomas's ostensibly to see Dr. Beaney (but again he is a "no show"), have the final fitting of the mould and undertake what is described in a handout as a planning session for my "individual treatment plan".

The day starts ominously when I switch on my mobile to hear that my 9.30 appointment has been changed to 9.30! There is no contact number to ring and I'm on my way so nothing I can do about it. The morning maps out as follows:

09.10 - Arrive early and welcomed by a nurse named Jane. She explains I will go back into the Mould room for a final fitting before a session in the Simulator room (as described in the guidance notes). The morning will conclude with a meeting with one of the Chemotherapy nurses.

09.25 - Julian Chapman takes me into the Mould room and makes adjustments to the mould (the swelling on the left of my face has gone down further as expected).

09.40 - Adam Dobson, Radiographer, takes me to the Simulator room where a female colleague joins us. I acknowledge that the mould feels tight and they make further

adjustments. I'm in the room for 25 minutes and given an envelope with a label showing that my appointment for treatment is set for 04.10.2005 at 2.00p.m. In treatment room "Elekta 1".

10.10 - I call at the Chemotherapy ward and am fast tracked for a blood test (the most painless I've ever had). Afterwards Judith Guevarra, a Chemotherapy nurse, meets me.

12.00 - I arrive at my office in Holborn. It's great to see everyone. They all say how well I look and sound, with lots of encouraging comments. I'm struck by one of them - "if anyone is going to beat cancer, it will be you" says Karen Holland. The visit is a real tonic for me. I hear a couple of horror stories about colleague's experiences of St Thomas's and as if on cue at **12.30**, my mobile rings. It's Adam Dobson, the radiographer I met this morning. He wants to check I'm aware of an appointment for 03.10.2005 to do a "dry run" of the treatment in advance of the start on 04.10.2005. I'm not aware but will, off course, attend. Whilst talking to Adam he notices a "post-it" note on my file saying I'm to have an MRI scan tomorrow, 20.09.2005. Again, this is the first I've heard of it. Adam doesn't know the time the appointment is set for and asks me to ring x 89033 (020 7188 7188) to find out. I call MRI and find Dr. Beanery's secretary set up the appointment last Friday. It's set for 2.00 but they have plenty of slots and agree to change it to 11.00.

I leave my colleagues and walk to London Bridge. I feel tired when I get home and my legs ache - it's been a long walk, a bit too long today, but I need to stretch myself and constantly find new boundaries. In what becomes a daily routine, the afternoon is spent napping on the settee.

20.09.2005 - 1st post op MRI scan

I get to the MRI unit at St Thomas's (Lambeth wing, 1st floor) at 10.40 and complete a safety checklist. Two problems. In response to questions "Have you had an operation in the last 2 months?" and "Have you ever had an operation on your brain?", "Yes - brain tumour removed 28.08.2005". Christine, the nurse in charge is concerned a scan so soon after major surgery could be dangerous. Furthermore, I'm listed as a private patient and am asked to fill a further form re the costs of the scan. I refuse. I explain I'm an NHS patient but that certain aspects of my treatment (a specific 6 week course) are being paid for privately. The important issue is whether it is dangerous to proceed. She goes away to check. Whilst she is away I look at the terms of the Norwich Union Healthcare letter. The coverage is for "Treatment/Investigations" and on reflection I consider the cost of a scan to understand the starting position, reasonable. Whilst this is not my money, I will not let my misfortune be used as an excuse to subsidise incompetence.

Christine, returns having been given the go ahead from one of the radiographers. I am not asked to complete the private patient form and the scan goes ahead. A couple of scans are taken having injected some fluid into me to enhance the images. She is friendly and thorough and I thank her for her time, apologising for the confusion surrounding my appointment.

My confidence in St Thomas's is at a low ebb. There is little motivation of me as a patient (that will not diminish my will to fight) and every appointment seems surrounded in confusion. On the train I draft a letter to Dr Beaney outlining my concerns. However, I don't have a contact number or address for him and as speed is important I telephone

Rachel MacArthur instead.

Are there any other appointments I should be aware of? She apologises for the confusion but everything now seems to be covered. I'd hoped my treatment could be set for late morning (the first appointment is set for 2.00), so I could miss the morning rush hour but still get back in time for a lie down in the afternoon. She tells me they will try to tailor appointments to patients needs after the first one.

29.09.2005 - Return to France

Another break in appointments, so another opportunity to unwind in France. It's another 600 mile drive for Lisa down to warmer climes. I'm feeling really good. How can I feel this good yet be so ill?

03.10.2005

Arriving at the Oncology unit's reception desk, they have no knowledge of my appointment and ask for my appointment letter. I explain I was notified by telephone and am directed to the waiting area of the Simulator room. I'm seen by David Frost, Rachel and Collette. Fortunately, they are aware. I ask a few questions e.g. there was talk of my dosage of Dexamethasone being increased once treatment starts - will it? - They have no idea and more worryingly, are unaware this is a joint Radio/Chemotherapy course.

Later I see Dr Beaney. It's my first meeting with him. I draw his attention to the patient consent form drawn up by Teresa Guerra and its "benefit" of "No cure". "I didn't see that and I disagree with it". He is clearly annoyed at the statement – excellent. At least the two of us are working to the same agenda.

We talk about the causes of brain tumours but basically, medical knowledge is limited to what doesn't cause tumours. He discounts mobile phones and I concur saying that if my usage of a mobile was sufficient to trigger a tumour then 100's would be dropping in the street each day. So why me? If I'd been a smoker on 20 a day, I'd have been able to rationalise a diagnosis of lung cancer, but this brain tumour, what have I done wrong? His diagnosis is not dissimilar to my GP's with "It happens"! Still, no point in crying over spilt milk. Lets move on and talk solutions.

I return to my theme of "what can I do?" Along with the usual advice about a good diet, exercise etc., he suggests 3 glasses of red wine a day (the nurse at King's suggested only 1) with Chilean red wine being particularly recommended as it's high in flavanoids. It seems I have a consultant that's done a study on red wine and its impact on cancer - the office is really going to believe that one! I tell him I have a cellar of French red wine but that Chilean is my wine of choice in a wine bar as it offers better value. He seems content that I'm doing the right things.

I also mention the success of my BUPA health check in June. I just want to reiterate the message that experiments on me will not be distorted by failures elsewhere. I'm really very fit!

Talking of my BUPA health check brings back memories of my little "joke" at the time of "you'd think they could have found something that would justify a 6 month sabbatical"! Do not make jokes like that again, Dave.

Surviving and Thriving – my encounter with cancer

Overall, there are grounds for optimism. Temozolomide is key, and he feels, the de facto drug within 5 years. My age and the pace I recovered from the operation are both strong grounds for optimism. He tells me to keep physically and mentally active. The worst thing to do is give up. Don't worry I won't. Some 4/5% of patients do exceptionally well - join them.

I like Dr Beaney and am reassured by him. I will need to make sure that he is on top of things as the two units seem to be working independently.

Treatment Phase 1

04.10.2005 - Commence the dual treatment

I call at the Chemotherapy Unit to pick up my course of tablets but the pharmacy has still not delivered them and someone is dispatched to pick them up - why am I not surprised? They arrive 30 minutes later and a nurse talks me through them. For 42 days I am to take 140mg of Temozolomide each day, on an empty stomach, before breakfast. I'm also to take 10mg of Domperidone, an anti-sickness drug, three times a day.

Today's radiotherapy session is booked for 2.00 and so I'll take them when I get home, which I optimistically say will be shortly after 3.30. They want to keep an eye on my blood levels weekly and I'm booked in for a test on Monday. All in all, there is an atmosphere of competency in the Chemotherapy Unit that gives me confidence.

I report to Elekta 1 in Radiotherapy at 1.50 for my 2.00 appointment. I'm eventually seen by Krishna Patel at 3.10pm. No apology or explanation is offered. I suspect it's just part of the general malaise that surrounds this unit. I'm really regretting not exploring with my employers healthcare team the prospects of getting into a privately run hospital.

Krishna was unaware this was a 6 week joint radio/chemotherapy course and tells me that treatment will be done over 2 phases. *Post treatment note: I never see Krishna again but reality is that it's done over 3 phases.* At 3.20 I'm on the Radiotherapy bench for a 20 minute session.

I take the Temozolomide and Domperidone anti-sickness tablets with a glass of water at the hospital. 3 hours later I'm sick and am so every 15 minutes. That night I can't even keep down my Phenytoin capsules. It's not violent sickness, just consistent until everything inside, is out!

05.10.2005

I sleep OK but I've been sick again this morning. As I've now missed 2 sessions of Phenytoin. Lisa & Lauren escort me to the hospital, just in case I collapse. *Post treatment: note despite predictions, this is the last time I need to be escorted during the 6 week treatment period.* Arrive at 12.38 for my 1.00pm appointment with Radiotherapy. I'm eventually seen at 1.30pm. Again, no apology or explanation offered. I tell the nurse that I was sick last night and again this morning. She suggests I speak to Dr Beaney. Although I'm on an anti sickness drug, it's a question of finding the correct dosage.

At 1.50 I call in at the Chemotherapy ward and see Vicky. Pending a full prescription she gives me two 1mg tablets of Kytril (Granisetron), a powerful anti-sickness drug. There seems a real disparity between the two units. In Radiotherapy, nothing is right first time, but when you ask a question in Chemotherapy you can sense them thinking through for a constructive answer.

06.10.2005

Arrive at the Chemotherapy unit at 12.30. The Pharmacy have not dropped off my new sickness drug so, rather than waste nurse's time, I take the prescription to pharmacy. I can take this drug (Cyclizine 50mg) alongside my existing supply of Domperidone.

My 1.00 radiotherapy session starts at 1.30. It lasts only 10 minutes and as it's my first week the nurse wants me to see a doctor from the specialist team. At 2.20 I see Rachel MacArthur. I tell her of my bout of sickness and that a new drug has been prescribed (the details have not reached my file yet). She reassures me, saying there are 100's of sickness drugs. It's just a matter of finding the one that works for me. She wants to set up a weekly blood test but I tell her the Chemotherapy team has already done this with one scheduled for Monday.

She asks if I have any concerns. I tell her few people seem to realise this is a joint radiotherapy and chemotherapy course, consequently I have no idea if the actions of one unit have implications for the other. She will note this on my file but says the radiotherapy treatment is the "bog standard". I ask what the MRI scan showed. She replies that it shows I had an operation! I sense she feels the scan was unnecessary.

07.10.2005

Clock in at 11.40 for my 12.00. Am seen at 12.40 for a 10 minute session. I mention that I feel slightly nauseous. Janine says I'll probably feel rough over the weekend as the treatment sinks in. It's Elekta 2 on Monday, upstairs in South Wing.

The new sickness drug (Cyclizine) isn't working. I'm feeling increasingly nauseous. Lisa calls Rachel MacArthur at 6.30pm. She acts quickly, getting in touch with Dr Patel at my local surgery who faxes a chemist an order of Kytril sufficient for the weekend. It works. I feel nauseous throughout the weekend but at least I'm not sick.

Thanks for your promptness Rachel. This episode gave us both assurance that support is there if needed.

10.10.2005

Start with another painless blood test and then down to see Alex in Chemotherapy to tell her of my continual feeling of nausea. She refers the matter to Dr Beaney but in the meantime gives me another 2 Kytril tablets. She'd like to wean me of it, as it's a very powerful drug that gives terrible constipation. I tell her I'm sorting that with plenty of prunes.

Off to Elekta 2 which is indeed upstairs as advised by Elekta 1 but upstairs in South Wing, quite some considerable distance away. However I'm seen on time for a 10 minute session. There is an atmosphere of calm in this unit but I'm back to Elekta 1 tomorrow.

11.10.2005

I'm called for my Radiotherapy appointment at 1.45 and am out by 2.00. I'm finding deterioration in my eyesight. It seems the treatment may be irritating a nerve, but this will stop once the treatment stops. At Chemotherapy I'm told I can wait 2 hours for my Kytril prescription or call back tomorrow. I choose the latter.

12.10.2005

Call at Chemotherapy for my prescription but it's not ready and I'm asked to call back

after my Radiotherapy session. 12.55 I'm back at Chemotherapy and its ready 5 minutes later. I take the Kytril prescription to the Pharmacy. It's ready after 30 minutes, as they said, but they tell me to take just one tablet a day not 2. Surely this change in drug levels is something that should have been discussed with the patient?

13.10.2005

Arrive at 10.40 for my 11.10. I'm seen on time and then its out to await Dr. Beaney. At first I see Rachel MacArthur but Dr Beaney soon joins us. I'm doing well and the aim is to keep me at my current active state for the duration of my treatment.

14.10.2005

Report to Radiotherapy at 10.50 for my 11.20, but they have a gap and I'm seen straight away.

That afternoon I have another look at the Internet. Yes Rachel, you are right, there is a lot of funny stuff out there but don't worry, they will not get a penny out of me. I find various press releases and start to understand what, in cancer terms, a "breakthrough" or indeed "sensational breakthrough" is. Well it's something that is measured in months and almost certainly not applying to Brain Tumours. Oh well, fight on.

16.10.2005

This turns out to be my last night of uninterrupted and unassisted sleep until 30.10.2005.

17.10.2005

It's been another bad night's sleep. Another Monday, another blood test, the difference being that I feel this one. Apparently the area is too sore to use again, so it's over to the other arm next time. I've time on my hands and discover the restaurant prior to my Radiotherapy session.

That night I have great difficulty in sleeping, not getting off until 4.00. Is this a side effect of the anti sickness drug?

18.10.2005

Usual 25 minute wait for Radiotherapy. Two new girls have a lot of trouble with the alignment. Janine is on hand, checking their understanding.

She asks if I have still been feeling nauseas. I tell her "no", but mention my lack of sleep.

I see Vicky in Chemotherapy for a blood test form and some more Kytril. She gives me a couple but wants to refer it to Dr Beaney as Kytril is a powerful drug and not something to stay on too long - could this explain my lack of sleep? I agree to call back tomorrow.

19.10.2005

Call on Vicky in Chemotherapy. She tells me Dr Beaney wants to see me tomorrow to understand why I'm still being sick - I'm not, Kytril is working! In the meantime she gives me 2 more Kytril. I check in at the Radiotherapy Unit at 11.15 but they have a backload and at 12.00 I'm whisked off to Elekta 2 in South Wing. The nurse takes me through the old part of the hospital with its grand pillars and statues of Victoria and Edward VI (its founder). I'm feeling good and lunch in Toms 2. Last nights sleep was better, but still only c3 hours.

20.10.2005

Arrive 11.25 for my 11.45. With few patients around, I'm starting to think that Elekta 1, is closed when at 12.00, I'm called. A longer 20 minute session as they are taking photos to compare with the original planning measurements. A tip from one of the radiographers - "try Sainsbury's Taste the Difference fruit juice range - they are "delicious". Yes I know there's no scientific evidence for the health claims, but what's the worst that can happen? I discover a new drink I like the taste of.

At 2.00 I see Dr Olivia Chan from Dr Beany's team. I tell her of the removal of Codeine from my daily treatment without recourse to Paracetamol. Appetite is good and I'm taking long walks. On the debit side, I can't sleep and have mild constipation – uncomfortable, not painful. She tells me to take Senna tablets (I have a stock) for the constipation. I haven't taken any yet. I've got enough chemicals rattling around in my body. I'll treat this naturally with an increased dosage of prunes rather than have another drug.

She asks me what medications I'm on and when did I last have Chemotherapy - shouldn't she know? On hearing I'm on Dexamethasone and Ranitidine, tells me to consolidate the morning and night dosage into a single morning dose. Dexamethasone is a steroid, and keeping it away from bedtime can only be good. I confirm I'm not suffering from any of the usual symptoms i.e. headaches, sensations in my fingers etc.

21.10.2005

I'm seen promptly for my Radiotherapy session. It's led by Janine and goes off smoothly. I mention my lack of sleep and Dr Chan's theory that consolidating the Dexamethasone into a single morning dose will solve it. This aside, I feel in good shape.

She asks if I'm losing weight. I have but with my appetite back, hope to reverse this. Apparently it's good to keep weight stable.

Back home in Bexleyheath, I pop along to see my GP, Dr Fish, for our 6 weekly sessions. He immediately comments on how well I look. I tell him of Dr Beany's optimism for my prospects and boast of my full head of hair. The only cloud on the horizon is the lack of sleep. He pinpoints the Dexamethasone and I tell him this was Dr Chans analysis as well. He gives me a prescription for Temazepam tablets (10 mg) but counsels me not to use for more than 3 consecutive nights. I tell them of their desire to wean me of Kytril. "The reason they want you off Kytril is because it's expensive! If it works for you, stick to it!" A quick reference to a handbook reveals that the price has fallen. "Oh, it's now only £6.50" he says. Still sounds a lot to me. Goodness knows what the Temozolomide costs. It's good to deal with Dr Fish - he gives you confidence. He reminds me to call back within 6 weeks, or earlier if ever I want to.

Post Treatment note as at 27.01.2007: getting my weight back is a problem - I'm still a stone down from my pre-operation days and on the last or penultimate hole of both my belts. 26.03.2007 - I'm on my way back with the belt today on the fourth hole. 03.09.2007 - belt now firmly on hole four.

That night I avoid taking the sleeping tablets in the hope that Dr Chans solution works -

it doesn't.

22.10.2005

I'm tired after the lack of sleep but otherwise feel fine. That night I take 2 Temazepam tablets and I'm off within minutes.

23.10.2005 - Hair going

After the success of last night I see if I can manage with just 1 sleeping tablet. It helps but it's not as good. Having boasted to Dr Fish that my hair was still there, I find today it's rapidly leaving. Rachel had warned me, it should come back, just maybe not in the same form. I'm unconcerned as long as it doesn't come back ginger and curly.

24.10.2005

Another Monday, another blood test. A new nurse but it's painless. What I can't understand is why they are so slow in comparison with Queen Elizabeth Hospital nr Shooters Hill. The counter was on 21 when I arrived and on 22 when I left 20 minutes later. I shouldn't complain. As a Chemotherapy patient I'm always fast tracked for what are the most painless blood tests I've ever had. I suppose it's the project manager in me coming out.

Off to Elekta 2 in South Wing. The sign says they are running 1 hour late but I'm seen at 5.15, just 30 minutes late. They seem to have a lot of trouble with the alignment, but get there in the end.

With my Caley (Inverness Caledonian Thistle F.C.) hat on I walk over to Charing Cross for a train. A news item on the big TV screen catches my eye. There's been a breakthrough. Scientists have now proved that wrapping up warm can help stave off colds. Now, my mother was nagging me about this when I was just a little fella. I obeyed, but had no idea she was talking without any scientific back up. Just goes to show. Pour me a large glass of pomegranate juice please.

Fingers crossed for a good nights sleep. I'm going to try to get through without sleeping tablets.

25.10.2005

Another bad night. It's getting worse with no sleep at all. I must take Temazepam tonight if not I won't last the week. Other than lack of sleep and a sore eye, I'm feeling fine. It's these medics that are telling me I'm ill!

I clock in at 11.15 for my 11.45 Radiotherapy session. Janine greets me with a "got a new hair cut" comment. I tell her of my boast on Friday that it was still there but we agree it's the least of my problems - provided it doesn't come back ginger and curly.

Post treatment note = it's back, no problems.

It seems a number of her patients are presently having insomnia problems. She is pleased my GP is keeping an eye on me and tells me to take the sleeping pills so that I'm not worn down by the weekend. She asks if I'm going to bed late or eating late and I'm able to confirm I'm not. She gets her colleague, Deborah White (who I had not met before) to leave a message with Jill McCall, a radiographer that can teach me Reflexology and relaxation techniques.

This was a good session - I alert the team to a problem and they go away to find a solution. I'm left wondering why Dr Chan could not have suggested this last Thursday. I

leave feeling good, if a little tired through lack of sleep.

26.10.2005

Decent nights sleep having had one Temazepam tablet and then a second that sent me off after 3 minutes. Left eye still sore with hair now coming off on the top and right side, as well as the left. I have a good walk down Whitehall but I'm beginning to feel the cumulative effect of the treatment and arrive tired.

Arriving 15 minutes early, I'm whisked into Radiotherapy straight away. They want me to have a blood test in advance of me seeing the Doctor tomorrow. I explain that the Chemotherapy Unit has me booked in for a weekly one. They are happy with this as Chemotherapy will tell them of anything amiss. I must check this with the Doctor as communications seems to be a weak point in this hospital.

27.10.2005

The 2 Temazepam kept me asleep until 2.30am but after that I'm restless. I hope this is just a blip as I want to go without them tonight.

I receive a letter dated 28.09.2005 saying that I have a 10.30 appointment on 30.11.2005 with the Speech & Language Therapy Service at Queen Mary's Hospital Sidcup. My speech is fine, although goodness knows what the treatment will do to it.

I'm in Elekta 4 today - it's the same process but apparently a slightly different sound - not that I could tell. The session goes off smoothly and I'm off to see Rachel in Dr Beaney's absence.

He sends his apologies. Apparently the hospital is being inspected and he needs to be interviewed. I tell her of my insomnia and eyesight problems, the latter of which I put down to moulting hairs. She is not convinced and feels it's a common reaction to the treatment. The solution is a week's course of penicillin, a double dose of Dexamethasone and some eye ointment. I later read that eye infections are a side effect of Dexamethasone - I'll give it a go nonetheless.

She is pleased that my GP is keeping an eye on me and concurs with his prescription for Temazepam.

I meet Jill McGraw, the reflexologist that Radiography set me up with. In a fascinating discussion she tells me of the snake side of my brain - survival instincts, and the donkey side - sleep/day. I need to get my donkey side working. She tells me to think through before I go to bed, the things I'm going to do tomorrow. If I can't sleep after 20 minutes, go downstairs and watch TV. It's important to get up at the same time each day. I'm doing this anyway. She invites me to come back for hypnosis lessons if I'm still having problems.

I tell Rachel of the Radiotherapy Unit's desire to put me through a blood test but were happy on hearing the Chemotherapy Unit had already arranged a weekly test. Rachel was able to tell me that the results were coming back normal. I also tell her of Chemotherapy's desire to wean me off Kytril, but at the small dose (1mg) I'm on, she's not concerned. Overall she is very pleased at the way I am doing.

That night, I try Jill's techniques. I need to get up and watch TV but they did help.

29.10.2005 Taste buds AWOL

It's my in laws wedding anniversary and they take the family out for lunch. On the way back Lisa comments on just how good the wine was. Oh dear, our choice of wine is very similar and I thought it was plonk. One of us has lost their taste buds and with the cocktail of chemicals I've had, I suspect it's me. Got to get this sorted for Christmas.

31.10.2005

After a good night's sleep, I report to Elekta 1 and am taken to the Simulator room - they want to check their plans before starting Phase 2 tomorrow. I should have checked, but on day 1 of my treatment on 04.10.2005, Krishna Patel told me that Phase 1 would be for 10 days. *Post treatment note: Phase 1 becomes 17 days, Phase 2, 3 days and Phase 3, 10 days.*

This "re-fit" takes about 30 minutes and then it's back to Elekta 1 for the treatment.

Janine tells me that Phase 2 will feel no different to me. I'm then called to see Dr Beaney. I tell him I'm feeling good with last night being my first night of unassisted sleep since 16.10.2005. I confirm I'm suffering from none of the usual problems of headaches, tingles etc. There's no mention of the increased dosage of Dexamethasone on my file, but after an eye test he tells me I can reduce the dosage to 6mg and stop using the eye ointment and penicillin from Thursday.

He tells me I'm doing very well. Phase 2 will last for 3 days before moving on to the third and final stage of 10 days. Basically, they are treating the area that showed up on the scan + 3cm. However, the cells move around and consequently, they want to get them all. Encouragingly and without prompting from me, he says the **objective is to get a cure**.

I ask what happens after the 14 November. They will wait 6 - 8 weeks and then take an MRI scan, injecting some fluid to enhance the image. This will determine the base position and will be followed by a scan every few months. He asks about my healthcare cover and suggests it might be better for me to see him at his Harley St base. He is looking to progressively manage down my steroid dosage.

We talk about my aspirations to return to work rather than retire. He is surprised that RBS have not contacted him yet, but this can wait.

It's then off for my regular blood test - bizarrely they can't get any blood out of my left arm and so it's over to the right one.

01.11.2005

After my second consecutive unaided nights sleep, a late appointment makes me decide to do a very long walk and visit the office. I get off at London Bridge and walk to my Holborn office via the Millennium Bridge at the Tate Modern. My hair is still falling out and by now I'm sporting a lopsided Mohican. A girl in the lift asks if I cut my own hair - there is no easy way to tell her and I don't hold back. She looks as if she wants the ground to swallow her up!

It's good to see everyone, as well as get their encouragement. After my last couple of visits, I wondered if I'd been looking too fit to justify sick leave. However, it's clear they are a little shocked to see me bereft of hair. Much later I find out that people were indeed very shocked by my appearance. So much for me thinking they thought I was

skiving. Only the day before Dr Beaney had commented on the absence of contact from RBS. Looks like news of my ad hoc visits to the office had got back to Edinburgh. After an hour, I set off for the hospital, picking up a sandwich on the way.

I'm in Elekta 2 today. The appointment is for 2.30 but it's 3.25 before I'm seen. It's a 30 minute session as they have a lot of trouble with the alignment and they want to take more photos as it's the start of Phase 2.

I try to type up my notes each day but I'm finding my eyesight is not up to the job. Thank goodness I put the spell-check on that last piece. I think I'll save up the notes for a while until I get an improvement.

02.11.2005

Bad nights sleep (unaided) but otherwise feel good. A brisk walk from Victoria, and into Radiotherapy. The mask is getting tighter (but bearable). Janine thinks this is probably due to the brain swelling.

03.11.2005 - attempt to tell Lauren

A couple of Temazepam gave me a good night's sleep and I feel good. I do a fast paced walk from Victoria and am seen by the usual team. I walk to Charing Cross via Whitehall. I'm tired when I get back and the eye seems to have got a little worse after yesterday's improvement.

Back home I'm playing with Lauren. I'm fighting but what if it goes wrong? I can't leave it all to Lisa to explain. I decide to tell her something is amiss. She knew granny was "poorly" and went to heaven. She knows that Daddy is poorly and goes to the hospital each day. I tell her that one day "I may have to go to hospital and won't be able to come home again, but it's not because Daddy doesn't love you, he would do anything to be with you and Mummy it's just" - I'm interrupted, "No, No, No Daddy. You don't have to stay away. Mummy and I will come and get you. You don't have to stay away". I grab her in a hug, giving me the seconds I need to compose myself. Fight this Dave, do not let her down.

04.11.005

No Temazepam and a mixed nights sleep, but a brisk walk from Victoria perks me up. A prompt, incident free session at Radiotherapy. Home to the settee via Charing Cross. *Post treatment note. The nearest station to the hospital is Waterloo, but the daily routine of Charing Cross or sometimes Victoria, was used as it gave me a longer walk.*

07.11.2005 - Cease Temozolomide

No Temazapan, hence I'm watching TV until 4.30 a.m. I'm tired but put in a brisk walk from Victoria. I thought I'd lost my appointment card but it's with the Radiotherapy Unit and the session is over in 10 minutes.

Off for a blood test where she drops the needle and blood oozes out - a taste of things to come I wonder.

Later Dr Chan calls Lisa and then at 6.00 calls me to check that I've got the message. My platelets are low and I must come off the Chemotherapy immediately. There is just a week to go I protest. I point out that it's just possible that I'd overdosed this morning but she's insistent. She wants to see me next day. In the meantime, I'm to go to my

nearest A & E if I start to bleed. Avoid wet shaves and take care brushing your teeth. Going forward, I'm going to have daily blood tests and if they fall too low, a blood transfusion.

Tonight I take a couple of Temazepam and am swiftly off to sleep.

08.11.2005 - Confusion in Radiotherapy

On reporting to the blood test unit, I'm steered away from a student nurse ("it's your decision!") and into one of the experienced hands. She says "what lovely veins you have - for a chemotherapy patient". Such flattery and it's another painless one. I clock into Elekta 2 12.40 for my 2.10 appointment but it's 2.55 before I'm seen. "Is it Phase 1 or Phase 2?" says one radiographer to the other. "Phase 2" comes the reply. "Phase 3" says the patient. A hurried consultation confirms my view. "Is it the Black marks we should be using?" the first radiographer asks. In the silence I tell them their colleagues in Elekta 1 are working to the Green ones. The second radiographer agrees. This does not inspire confidence in the patient. It comes just a couple of weeks after a teenage girl in Glasgow was given 17 overdoses. I can understand how that happened, but just how many times? Luckily I have my wits intact, but how many don't? *My answer comes in March 2008 with an NHS report revealing 1,854 radiotherapy mistakes. Up 2.6% on the previous 12 months!*

Back to the Chemotherapy Unit to get the blood test results and see Dr Chan. My Platelets count has got worse, it's down another 1 to 21 and "Normal" is 145 - 400! I'm able to tell her that I've not had any headaches, bleeding or bruising and am keen to finish the course of Temozolomide. As Rachel MacArthur was telling me at the outset, Radiotherapy alone was good for only a year, so I've nothing to lose. She goes away to refer the matter.

It's not good news, I may need a blood transfusion if the Platelets continue to fall, she says they may fall for several weeks, can't see how, I've only got 21 of them! I stress how keen I am to continue to the end of the course but it's no use, Dr Chan says the risks far outweigh the benefits i.e. bleeding that will not stop. I'm to continue with the Radiotherapy but with daily blood tests. I should continue to avoid wet shaves and take care when brushing my teeth.

I'm devastated by this decision to stop the Temozolomide, but think what Dad would do if he had such news - not even blink! I think about my late father a lot during the treatment. Lisa, Lauren and bloody mindedness are my reasons for fighting. Dad gives me the courage. As a P.O.W. of the Germans he was on the brink of execution, whilst a world war earlier, his father sustained terrible wounds on the Somme. Later Dad battled with Parkinson's. He took them all on with courage and dignity. How can the latest generation of Grant behave any differently?

What I can't understand in all this, is why do I feel so good? It's you medics that are telling me I'm seriously ill.

09.11.2005

Temazapan gives me a good night's sleep and I walk down from Victoria, feeling good. Having collected the blood test form from Vicky in Chemotherapy, I report to the blood test unit. They take 2 samples — one from the usual place and another from my left hand. The second one, she explains, is because they may want to give me some blood. Later in the day I find out they could have got this info from a single blood test — no matter.

I'm seen 50 minutes early by Radiotherapy. After yesterday's debacle, it's good to be back with the usual team.

Back to Chemotherapy for the results of my blood test but my timing luck has run out and inevitably the results are not back. They arrive at 12.30 and at 21, are the same as yesterday - carry on unshaven.

10.11.2005

Lisa has an idea to help me sleep. Take a bath in the evening and douse myself in Chanel No 5 lotion. It will relax me she says. Not all that macho but I'll give it a go. Result - it works and I sleep OK.

A very slight feeling of nausea on the train but my walk around St James Park sorts it. Another blood test - seems they are testing for:

Group & Antibody screen and
FBC & Diff (I must ask what this is)

On other days they've tested for:

Renal Profile (Chemical Pathology)
Liver Profile (Chemical Pathology)
Bone Profile (Chemical Pathology)
Aspartate (Chemical Pathology)

Off to Radiotherapy and a cheerio to Janine who is flying home to South Africa tomorrow. I'm sorry to see her go. She was very good and a nice person. I then see Dr Guerra. She tells me I have done very well and not to be concerned about coming off Temozolomide early - I've had the benefit off it. Platelets remain the concern (now 15) and she wants another blood test tomorrow. This will determine if I finish Temozolomide or need an emergency blood transfusion. Decisions on how to manage out Dexamethasone will be made on Thursday. I ask what the trigger point is for action on my blood tests, rather than monitoring - she will check.

I walk back to Charing Cross via Whitehall. I'm tired when I get home and crash out on the sofa.

11.11.2005

Chanel No 5 but no bath or Temazepam mean that I'm back up watching TV until 3.30. I'm tired in the morning but manage a good walk from Victoria. When collecting the blood test form I bump into Dr Guerra. Again she reassures me about coming off the Temozolomide early, telling me to put it out of my mind. I mention my June BUPA health check, when my platelets were at 177 — it will come back she says. I report to the Chemotherapy Unit in case I need to come in for a blood transfusion and see Dr Guerra again. No blood transfusion, but call into Guy's on Sunday for a further test. They will decide if I need a transfusion. Today's test put my level at 20.

12.11.2005

Took 2 Temazepam last night and had a good nights sleep. Feel good and have an active day culminating with a return to the PC, typing up some of my backlog of notes.

13.11.2005 - To Guy's hospital and a Sunday blood test

Chanel No 5 and a bath give me a reasonable night's sleep. Lisa and Lauren drive me up to Guy's where I'm seen by a nurse named Janet. She's not aware of my visit but later finds a "post it" note advising her. If I do need a blood transfusion it will be bad news as she has no spare beds. She comments on what lovely veins I have - for a Chemotherapy patient! The result is the same as Friday, another 20, so I am free to go. As we leave I spot a notice board with pictures of the "team". It includes a photo of Dr Beaney. This team approach is good. Why is it not done at St Thomas's?

14.11.2005 - Final day of Radiotherapy

I get a call at home asking me to come in early to see Dr Beaney. A blood test is done showing a reading of 21. He says I have coped exceptionally well but coming off the chemotherapy was correct due to the Platelets issue. However, this should make no difference to the effectiveness of my treatment. Platelets count should be in the 145-400 range but below 40 they monitor closely with 17 being the trigger point to take urgent action. I was at 15 last Thursday!

He wants to see me again next Thursday and my appointment is altered so I actually see him. He talks me through the three stages of Radiotherapy and says the aim is for me to now go away and forget about hospitals. I tell him of my appointment with Dr Costello to test my memory, which he describes as non urgent and can be fitted in later.

15.11.2005

My first day without a hospital appointment for an age. Lisa's solution of a bath and Chanel No 5 lotion is certainly a help if not a total solution. I need to keep up the exercise and have a 1 1/2 hour walk via Welling. I'm tired when I get back and crash out on the sofa. I'm trying to minimise my use of Temazepam and go to bed using the bath/lotion remedy.

17.11.2005 - What cancer have I got?

Its back to St Thomas's for a blood test and see Dr Beaney. The Platelets are at 41, so out of the danger zone but still well short of the normal 145 - 400 range.

I realise that I've never had a proper discussion as to the type of cancer I have. Everyone knows about the lung, breast and prostate cancers but what is this brain tumour cancer I have? He explains that it is a Glioma. I have a Glioblastoma Multiforme grade 4 - sadly the top and most aggressive grade. I'm pleased with myself for not showing emotion at this news, but it's not good.

He's pleased with the way I've handled the treatment and again tells me not to be concerned about coming off Temozolomide a week early - I've had the main benefit. Having finished the treatment we now need to manage down my dosage of Dexamethasone. I'm to go down to 2mg a day until 24.11.2005 and then 2mg on alternate days for a further week after which I finish. I should carry on with the Ranitidine for a few days after that, and then stop.

Next steps come in January, with an MRI scan to determine a baseline. He talks about a resumption of Temozolomide, probably 150mg for 5 days each month. (*We restart in February but it's at 270 mg for 5 days, with the latter 5 months at 250mg - quite an increase!*). He knows I want to return to work but I sense a note of caution in him and

we will discuss post scan. He asks about any neurological issues and I mention a slight twitching in both legs, but more so the left, late in the day.

I tell him of the comment Rachel made on 02.09.2005 that I would be considered for other trials (she mentioned food supplements). I wanted to reiterate to him my willingness to be involved in any legitimate test and refer back to my June BUPA health check. I think he understood.

He asked if it would be easier for me to see him at his Harley St office and I told him it made no difference to me.

He assures me that I have come through this very well and am doing all the right things, but the news of the intensity of the cancer makes me leave in a reflective mood. As I walk over Westminster Bridge I almost crack as I see a man with a little boy scarcely older than Lauren. Pull yourself together Dave.

24.11.2005

A blood test and then in to see Dr Beaney. I ask about my platelets level. He has to go and check but first wants to know how I feel. I'm feeling fine and exercising well. I'm still sleepy at the end of the day but the only neurological issue is a slight twitching in both legs. I'm able to answer a firm "No" to the usual questions of headaches, spots before my eyes etc. My platelets are back to a normal level of 152. The only debit point is that I am still vulnerable to infection with a white cells reading of 2.6 and Neutrophils figure of 1.3 - but don't worry things are moving in the right direction.

As for next steps, I'm to carry on with the Dexamethasone and Ranitidine reduction as agreed last week, but to carry on taking Ranitidine for a couple of days after I finish Dexamethasone.

All in all I've done exceptionally well and I'm to go away and forget about hospitals - at least until January, when I will have an MRI scan. What if the scan shows bad news? Seems it would be back to surgery or one of the many drugs they are developing. The pace I recovered from the last operation makes me comfortable with either option.

28.11.2005 - Dr Fish

I call in to see Dr Fish to update him on developments. I tell of Dr Beaney's comment that when the tumour returns I will either have another operation or try one of the many drugs they are currently developing. "Well they'd better hurry up and develop them" he responds. My thoughts entirely. I tell him of the scan in January and he encourages me to call on him after that, or indeed, anytime.

He too thinks I'm coping exceedingly well although today I can't help but feel a little down after last week's discussion about the precise nature and intensity of my cancer. It's good to deal with Dr Fish. He's someone outside the immediate cancer world, but still a professional I can talk to.

30.11.2005 - St Mary's Sidcup and final dose of Dexamethasone

My appointment with the speech therapist at St. Mary's, Sidcup. I see Photis Garipis for about 30 minutes. I thought I'd be subjected to tests but it's just a chat. The end conclusion is my voice has not been impacted (we laugh at Ray's assertion post op that my voice has got more Scottish). "There is nothing I can do about that" he laughs. Don't apologise. That's good. I'm going back to my roots! The brain may have lost some, what is termed, non-essential information, but basically, it's a clean bill of health

so far as speech is concerned. He will send a report to my GP and I ask for Dr Beaney to be advised as well.

It was interesting to meet him but how does this fit in with an overall patient plan? The answer is, it doesn't. It's down to me to make sure all the bricks stack up.

01.12.2005

Not the best of nights sleep, having got up 5 times to go to the toilet, but I don't feel tired. This is my first morning without Dexamethasone but I carry on with the Ranitidine. For the first time I have a glance at its potential side effects and find it's another one that causes depression - as if cancer wasn't depressing enough - still, I should feel good once I finish this one.

05.01.2006 - a scan

The date for my MRI scans at St Thomas's. I'm seen promptly and afterwards see Dr Beaney who puts me through a few hand and eye co-ordination tests. I'm OK. Get some Vitamin D he says. I start to ask what brand this one is sold as when he interrupts sensing what I'm about to say, "You can't buy it from Boots; you get it from the sun." A call to Lisa and she sorts a short break for us in Spain. As for the scan, he'll phone me with the results and see me for a next steps meeting in 4 weeks (fixed for 09.02.2006).

12.01.2006

As I have not had a call from Dr Beaney I turn up for my pre-arranged appointment, only to find they were expecting me next week and that he is on holiday. Instead, an appointment is swiftly arranged with Dr Brasil, one of his team. She asks me to pronounce "Baby hippopotamus" - which I do perfectly. I tell her of the clean bill of health I got from the speech therapist at St Mary's, Sidcup. She seemed to be under the impression that headaches and slurring had been an issue with me. I stress these were only an issue before removal of the tumour. I have not encountered these problems since.

I tell her I'm feeling good with no headaches or slurring. The MRI scan shows some enhancement, but this is expected. She wants to discuss with Dr Beaney when to resume the Temozolomide (he'd already spoken to me of a 5 out of 28 day regime). She comments the ease I've come off Dexamethasone is encouraging. I have an appointment with Dr Beaney on 09.02.2006 (I've checked it's on their commuter) and she agrees we can decide this then. At this meeting I will also be told of the warning signs to look out for. She is aware that Platelets were an issue with me and sends me off for a blood test to get a base line for the next stage of treatment.

13.01.2006 - Wicked sense of humour undiminished

Lengthy walks in the morning leave me needing a lie down in the afternoon.

Sometimes I go to bed but often, I just dose off on the settee whilst trying to watch an old film. This is the catalyst for a visit to the January sales and purchase of a large flat screen TV. A simple "no thank you" is insufficient to put off the salesman's push for me to take up an extended warranty, so I tell him there's no point in me paying to guarantee an electrical appliance longer than I have. The salesman wilts away as I hear Lisa admonish me with a cry of "David". I'm entitled to make jokes like that, I say. Lisa sighs, but I can see she's pleased to see me getting back to my old self.

02.02.2006 - King's and Dr Chitnavis

To King's for a 1.30 appointment with Dr Chitnavis. I thought this was for the 2 hours of tests e.g. memory, originally billed for 15.11.2005 with Dr Costello. I'm really up for this and feel excited, it's a challenge. However, I start to have suspicions that I've got it wrong as I go through the correspondence. Dr Costello is a *neurophysiologist* whereas Dr Chitnavis is on the *neurosurgical* team. My suspicions are swiftly confirmed. We greet each other and I say we have not met before but we have - he led my operation. I apologise and laughing, say "I was not at my best that day".

So what is this meeting about? Am I a private patient? I explain the background, but basically "yes". He tells me that sometimes the service for private patients in NHS hospitals is not as good as that given to NHS patients. As such, he proposes to lead the co-ordination of my treatment and transfer me to London Bridge Hospital. I'm pleased to hear someone talking about co-ordination - it's been my biggest concern surrounding the treatment. However, I don't want to lose Dr Beaney. I have a de-brief on the MRI scan set for next Thursday. Don't worry I will not lose Dr Beaney. They work together and he will speak with him and make sure he is at my London Bridge appointments.

He dictates a note to Dr Costello to say he is in charge, calling Rachel MacArthur telling her to get the MRI scan to him.

This all sounds good although the meeting is basically a sales pitch. An appointment is made for me to see him and Dr Beaney at London Bridge Hospital at 6.30, Monday 6.02.2006, bringing forward the scan feedback meeting from Thursday. I later telephone his PA, Mrs Soulla Ripley on 0207 357 0494 to confirm. I'm to go to the 2nd floor St Olaf House (SNS Associates offices), opposite the London Dungeons on Tooley Street.

On leaving I begin to have doubts. Greater co-ordination is great but I must not lose contact with Dr Beaney. I decide to ring Rachel to chat things through. First I ring Norwich Union to check I'm still covered. I speak to Lesley Goulton who tells me that as London Bridge is a "Select" hospital, I'm covered, both for consultations and subsequent scans. I thank her for her help and also pass on my thanks for the reassuring way Norwich Union handled my earlier calls - in contrast to the admin at St Thomas's.

Rachel returns my call. The unit at London Bridge hospital was set up a couple of months ago to give a better service to private patients (very much what Dr Chitnavis said) and I certainly will not lose contact with Dr. Beaney. I take the opportunity to tell her that Norwich Union have confirmed I'm still covered. All in all, I'm reassured.

06.02.2006 - London Bridge with SNS Associates

I have a 6.30 pm appointment. I must see if I can get an earlier slot next time. Rachel collects me from the waiting room and takes me up to see Dr's Beaney (in the chair), Chitnavis, Gullen plus one other. The scans are put up on a screen. Whilst it's good to get this group together, I'm unsure of the amount of collective analysis that has gone on. There is some swelling (Doedema?), which is broadly what was expected. Richard Gullen, the surgeon, comments that it's presently, surgically accessible and that "we could stop messing about and just whip it out". I'm surprised but not put off by this sort of language. Given the speed at which I recovered from the previous operation (home in 4 days) I confirm I'm happy with an operation if that is the recommended way forward. However, Dr Beaney previously spoke of me going back on Temozolomide for

5/28 days for 3 months, then have another scan and decide the way forward. There is talk about a local application of chemotherapy (Gliadel?) that is requiring approval from NICE. "Do nothing for the moment" is also raised as a possibility as I look so well. In the end it's decided we will go with Dr Beaneys original plan of taking Temozolomide for 5 days a month. Rachel will call me over the next few days to start it.

I'm offered the scan slides but decline, suggesting they will be needed for comparative purposes next time. Rachel jokes that I don't want to take them on the train - true, but a secondary issue.

I'm happy with this and Dr Chitnavis escorts me to the exit, giving me the card of the practice - SNS Associates. The partners are himself, Richard Gullen, Michael Sharr and Nicholas Thomas. I don't recall meeting the final two, although one may have been at the meeting. On the train home I look at the card. I'm struck by the absence of Dr Beaney from the list of Partners. He had spoken about me going to his Harley St office. If I have to choose between Dr Beaney and SNS, Dr Beaney wins every time.

09.02.2006

I'm due to see Dr Beaney today but at the 06.02.2006 meeting it was agreed that Rachel would cancel this appointment.

13.02.2006

At last Monday's meeting it was agreed that Rachel would call within the next few days with the arrangements for going back on Temozolomide. I've heard nothing - I think a week is a reasonable wait, particularly in view of Dr Chitnavis comments on why this practice was set up - to give private patients a better service.

I call Rachel. Her ansaphone says she is at St Thomas's today and tomorrow but she can be contacted via her pager. I leave a message, ringing back a few hours later. I'm not convinced the second message got through so I try to get Dr Chitnavis on the direct line he gave me - it just rings and rings. I try the practice manager, Mrs Soulla Ripley who I met last Monday. She tells me a letter is being sent to my GP and me from Dr Gullen, the surgeon that was at the meeting. I'm surprised at him taking the lead as the immediate way forward was meant to be back to Temozolomide i.e. a drug solution not a surgical one. If I want to know the contents before its arrival I should call his secretary (Carol 020 8297 4588). It's now 4.10 and Carol leaves at 4.00, so I should leave it until the morning.

A few minutes later Rachel calls. She is with Dr Beaney. By way of small talk, but mindful of the 17 overdoses the girl in Glasgow had, I ask her what the difference was between Phase 2 and Phase 3 (see entry for 08.11.2006). I'm immediately switched over to Dr Beaney. I suspect that hospitals have a corporate line on dealing with these questions but at least an answer from Dr Beaney has credibility - at least in my book it does. He explains the various phases and says that it would have been impossible for the Glasgow incident to have happened here due to the independent verification checks. Apparently only 5-10% of patients have a third phase. I assume from this, that had I not intervened, a check would have been made before the ray's started - I'm really not sure, but let's move on.

He asks if I could see him at Harley St (81-83) this Friday at 2.00. It's a more convivial and relaxed setting than at St Thomas's. I'm happy to go there. I'm not sure if I'm now in a bidding war between SNS and Dr Beaney, but if I am, I'm choosing Dr Beaney. I'm a lot happier getting this call and look forward to Friday.

15.02.2006

Copy correspondence arrives from Dr Chitnavis (not Dr Gullen, note 13.02.2006). It seems that Department of Health guidelines are that the patient should be copied in - I applaud this. The key letter is a briefing note to my GP. It says I'm looking good but although referring to the 05.01.2006 scan, gives no detail of the results. I don't recognise the spelling of the chemotherapy drug (Brinzolamide) but will check this with Dr Beaney. All in all, I don't find it a very good briefing note.

Treatment Phase 2

17.02.2006 - Harley Street and the Harley Street Clinic

And so to Dr Beaney at his Harley St premises. They are plush with the plaster work not unlike our dining room.

At 3.05 a nurse wants to do a blood test on me. I explain that one was done at St Thomas's on 12.01.2006 and that I'm here today for a consultation with Dr Beaney (at his request). He goes away to check. A few minutes later I see Dr Beaney. It's standard practice to do a blood test before giving out chemotherapy drugs. I'm able to answer a firm "No" to the usual questions on headaches and nausea. We talk about the session with SNS associates and the surgeons' comments about "just whip it out" but the conclusion is that for the moment I should go back on a course of Temozolomide for 5 days a month for three months, followed by a scan. The first dose, at 270mg (previously 140mg!) starts tomorrow. *Note: the 3 months extends out to 6 months with scans after 3 and 6 months.*

20.02.2006

To Dr Fish (at Westwood Lane) to brief him on developments and to get a certificate for a few more weeks. I confess I'm not ready for work but have an inkling to do something soon. He is not happy with this idea and I admit that the pressure on me to return is entirely self inflicted. Royal Bank of Scotland has a reputation of being a good employer, he says. The certificate is for 6 weeks when he will see me again, or any time earlier if I choose. If I wan't to go back to work earlier - which he does not advise, I must see him first. He does not trust me and makes me write this down! Thanks Dr Fish, I know you are looking after my best interests.

I talk to Norwich Union Healthcare to check I'm covered for Harley St. I tell them that it's a 5/28 day dosage for 3 months followed by a scan. A lady says this should be OK but puts me through to Mark Sherrin of their specialist oncology team. He confirms I'm covered but asks for Dr Beaney to call him after my next scan. Why am I being asked? Am I using up my credit? I ponder.

17.03.2006

Back to Harley St for a blood test in advance of my next dosage of Temozolomide. My Platelets are at 107 but nothing to worry about. This time I'm given a full pathology printout to keep. I'm low on 3 other items as well. At 2.00 Matthew announces that Dr Beaney will see me in 30 minute's. At 2.25 he gives me my prescription with a pledge that things will be a lot smoother next time.

Its clear that Dr Beaney has taken me off SNS Associates hands and I'm pleased. The cast of thousands at the February meeting just did not feel right. I show him the letter Dr Chitnavis sent Dr Fish. I comment that it gives no details of the results of the scan, furthermore, it refers to the stopping of chemotherapy treatment but sets no context i.e. I did 5 out of the planned 6 weeks.

The letter leaves the impression that it was a halt to the continuous treatment. He tells me the scan showed regression of the tumour but there would always be scar tissue probably with active cells. The aim of this stage of treatment was to have a scan with

no active signs of the disease. This is known as Adjunctive chemotherapy treatment, aimed at mopping up any remaining cancer cells.

I'm able to give him a positive response to his usual questions about headaches, sickness etc. Kytril continues to do the trick and I had only limited recourse to Domperidone - the dosage on Laurens birthday being very precautionary - I couldn't risk her having memories of Daddy throwing up at her birthday party.

On the debit side, my eyesight is poorer and 7/8 trips a night to the toilet do nothing for a good nights sleep. Notwithstanding this he is still pleased at the way I've handled the treatment, saying, "these are *very* powerful drugs". I raise the subject of back to work, but like Dr Fish, is not keen whilst I am on such a high dosage. In any case, my return must be in slow stages.

21.03.2006

To Dr Fish to update him and get a new certificate. He's his usual encouraging self. He does not want me back at work whilst I am on such a high dosage of Temozolomide and signs me off for a further 6 weeks.

13.04.2006 — Harley Street Clinic

Arrive at 11.30 and am asked for my registration card by the lad on reception in the Oncology unit. I've never had one, so he starts to type in my details but then acknowledges that I was here on 17 March so presumably I was registered! I have a sense that this is going to be a day of confusion! I'm told I need a prescription and respond that this should already be done, subject to a satisfactory blood test. A blood test is done by a cheery Chinese nurse who comments on what lovely veins I have. The blood test is not the painless sort I had at St Thomas's - nothing to moan about, just not reaching the peaks of excellence I'd experienced elsewhere.

I pop out for a sandwich and the receptionist promises to chase up my prescription whilst I'm away. I get back too quickly and I hear him asking where it is. A nurse asks me for my prescription! I go through the story - I arrive, have a blood test; if it's OK I get another 5 day dose of Temozolomide. This goes on for 3 months before I have another scan. She has no idea of this and says someone will have to look at my file - good! This is a shambles and comes on top of the confusion during my last visit. Joshua Atticks had said that steps would be put in place to ensure there would not be a repetition - this is worse and I'm left wondering if I should go back to seeing Dr Beaney at St Thomas's.

At 2.00, Dr Beaney telephones. The cloud of confusion starts to lift. My infection fighting cells are a bit low so he's reducing the dosage 20mg to 250mg. He wants to see me in a month but if I feel the need, call in next Friday.

He asks all the usual questions and I'm able to give an overall positive response but mention the tiredness, brought on by what are sometimes 8/9 visits to the bathroom each night. He asks if my urine is cloudy and is content when I tell him it isn't. I tell him of my poor eyesight but confirm that my long sight is OK. I raise the subject of a return to work. He's not keen, saying "don't rush back". We can discuss the matter when he sees me next month.

The "helpful" boy on reception tells me he does not book appointments but grudgingly puts me through to "Patsy", Dr Beaney's secretary. She can't make any appointments at present but promises to call me back.

19.04.2006

No calls from Patsy so I call her. She puts me in for 2.30 on 12.05.2006. I ask if Dr Beaney wants me to have a blood test first. She says “yes”, but there is no conviction in her voice, it’s just that “yes” is an easier answer than “No”.

03.05.2006

To Dr Fish to give him my 6 week update and get a new sickness certificate. He signs me off for a further 6 weeks telling me not to think about work whilst still on Temozolomide. He adds that I can have as long as I like - he understands what I’m up against and it’s good to have him. I’ll call back in 6 weeks, sooner if I want.

12.05.2006

My appointment with Dr Beaney is not until 2.30 but I arrive at 12.30 for a blood test after a good walk up from Victoria. There’s the usual vagueness when I arrive - this place is not set up to deal with “pop-in” patients like me.

A male nurse does the blood test. I suspect he hasn’t done many and I have not seen this technique before - a 12 inch pipe attached to the needle. It’s probably the most painful I’ve ever had i.e. not much, but not reaching the peaks of excellence I encountered at St Thomas’s. I later (much) get a copy of the pathology report. - Platelets back up to 123.

Joshua Atticks acknowledges me but that aside, I don’t feel like a patient in a patient plan - I’m just someone that’s called in.

At 3.15 I see Dr Beaney. He’s missed me the last couple of Fridays and I remind him that our discussion a month ago was to see him in a month unless I wanted to “come up next Friday”. It’s clear that he thought I was coming up. I remind him that the plan was for me to have a scan 1 month after the 3rd batch of Temozolomide, if OK, have another 3 monthly cycles. He clearly wants me back on the Temozolomide cycle quickly and will arrange a scan.

There’s the usual questions to which I’m able to give a positive answer. I tell him of my nocturnal visits to the toilet (6/7/8/9 a night) but confirm my urine is not cloudy. I also mention the tension in my legs particularly the right one (he would have expected the left one if anything was wrong) and my continued bad, but improving eyesight. He says that sugars may have altered in my eyes and that now was the time to try an eye test. Overall, I’ve “reacted well, with no evidence of an active disease”.

I raise the subject of the shambolic operation of the Harley Street Clinic and how it just does not seem to be set up for the “drop in” patient like myself. He asks me to illustrate my point, and I give him the example of a radiographer at St Thomas’s picking up that I was having difficulty sleeping. 30 minutes later, I’m fixed up to see Jill McGraw, a reflexologist. Whilst in the early days I criticised the operation at St Thomas’s there is a team – something that seems to be absent here. These are not just my experiences; each time I come, someone else seems to have the same issues. “I’ve been waiting 2 1/2 hours””, says a strong willed old lady . A bit later he pops over to the Oncology Unit and on his return concedes I have a point. As a result my next appointment with him will be at St Thomas’s at 10.00 on the 19th. He will try to arrange a scan and its analysis before then. Ideally this will be at St Thomas’s using the same machine. He checks I have the old scans but I tell him that whilst offered them at the SNS

Associates meeting at London Bridge in January, I declined, suggesting they'd want them for comparative purposes with the next one. As a result, Rachel had taken them. He rings Rachel and tells her to find them.

NICE/Temozolomide - what's happening? Sounds like the word is it will get a limited sanction i.e. for fit people. Not sure how this works but sounds like I'll be covered! I mention my bit of lobbying - who knows? He recommends I look at the NICE website. I'm signed off to 14 June and he agrees I can at least try a slow return to work, but if I'm not up to it, back off.

Although I was tired at the start of our session, his closing comments and the obvious enthusiasm behind them send me away with my adrenalin pumping "*clinically, things could not be better*". Adding that my bone marrow is holding up.

There's an office leaving drink at the King of Diamonds in Holborn and my adrenalin sees me charge over there to tell them the good news - so far.

19.05.2006 - St Thomas's and a Scan

I didn't get a call about a scan, so it's back to Dr Beaney, but as we discussed, at St Thomas's. I report to the Oncology Unit receptionist. She is surprised to see me.

Apparently Dr Beaney does not have a clinic today, but on hearing that I've been seeing him at Harley St, it's just possible that he has a clinic for me today!

He greets me at 9.55 and tells me my scan is today and they are waiting for me. I get there and find that two others are also booked in for 10.00, but it gets done (with an injection of fluid to improve the image). Dr Beaney popped up to look at the images and I'm sent back to him for the results.

"Looking pretty good", he says. "There is a rim around the tumour area but it's not bulging or active. What I did not want to see was any growing or distorting matter. It's inert matter and the brain is repairing." **EXCELLENT NEWS!**

He goes on to tell me that there could still be cancerous cells that they can't see and for that reason I'll take another 3 doses of Temozolomide (first starts tomorrow), have a scan and if the result is the same, no more drugs, just "keep an eye on me". I'll see him again, 9.00 a.m. at St Thomas's on 16.06.2006.

Vicky in Chemotherapy fixes me up with the next batch of Temozolomide and Kytril.

She wants me to have a blood test on 14.06.2006 in time for my session with Dr Beaney. I elect to have it at Queen Elisabeth's and she will phone for the results.

22.05.2006

An appointment letter for an MRI scan on 26.05.2006 arrives! Is it a mistake or have they spotted something? It's a mistake, Shelia says, with Maria ringing back next day to reinforce this message - in fact they can't understand how the letter was generated - there's nothing on the system.

13.06.2006

To Queen Elisabeth's for the blood test. Ouch! I'll have the next one back at St Thomas's.

14.06.2006

Vicky calls Lisa to tell her that my platelets are down to 93 but that it should not be a problem.

15.06.2006

It's a (slight) problem but it's not just my platelets that are down. White blood cells are down to 2.5 (Dr Beaney would like to see 3.0) and Neutrophils are at 1.7 (previously 2.0). As a result my meeting with Dr Beaney tomorrow has been put back to next Thursday at 2.00. I go in a bit earlier and have a blood test. If there has been a recovery, I'll get the next dose of Temozolomide. Vicky reassures me that it's just to make sure I don't have problems elsewhere once the treatment stops. She's right but I'm still disappointed.

22.06.2006

It's flowing today. Within seconds of my arrival, Vicky waves across, telling me to take the blood test form waiting for me in the basket. On taking the "red chemo" card a nurse shouts "fastrack" and seconds later, I'm having a blood test.

After lunching in Toms 2, can't be looking that bad, the cashier is again asking for my Staff discount card - I am a consultant, just not a medical one, A nap in the corner of the Oncology waiting area before Vicky comes over to give me my supply of Temozolomide and Domperidone but no Kytril. I tell her it's only 1mg which surprises her. My platelets are up to 191 and she puts my recent tiredness down to a cold.

Dr Beaney hasn't arrived yet but on this occasion I'm happy not to wait and see Emma Staples, the Senior Registrar instead. She seems knowledgeable about me. Once I've got over this tiredness she is comfortable in me trying a slow return to work. Two days at first and don't make them consecutive and certainly don't plan heavy ones. It will be at least four weeks after my last batch of chemotherapy before I'll feel much better. That means an end August return to work.

On getting home I see that the Temozolomide is plastered with stickers. Seems I should have been keeping it in the fridge. A warning of "CAUTION, Cytotoxic drug handle with care" makes a spillage akin to something out of Chernobyl. Oh well, I'm still here and it explains that slight tremor in medics voices whenever someone describes Temozolomide as a "very powerful drug".

20.07.2006

I see Emma Staples, the senior registrar. She asks the usual questions about headaches etc. The only problems I can report are a continued tiredness which she puts down to the results of fighting off a cold - how many battlefields can I expect my body to be fighting? I report my poor eyesight. She tells me how pleased they all are with my progress and not to worry about my tiredness; it's just the Temozolomide working its way out of me. She explains that it is a very powerful drug and I hear that slight tremor in her voice when she says "very". I'm due to finish Temozolomide on 23.07.2006 and she tells me not to expect any improvement for 3 - 4 weeks after my last Temozolomide session.

Still no NICE sanction for Temozolomide - its cost price for my 5 day dose is £865. Dr Beaney joins us and congratulates me on the way I've handled the treatment. A particularly encouraging sign was the ease with which I came off Dexamethasone and, my bone marrow is still holding up well. Next month, the end of treatment scan. Fingers crossed.

23.07.2006 - Chemotherapy Phase 2 ends

My last dose of Temozolomide. Now, get those chemicals out of my body. Onwards to the scan!

Monitoring & Recovery

31.07.2006

To Dr Fish for my 6 week visit. Sadly this will be my last visit as it's off to Tunbridge Wells on 15.08.2006. I ask for his advice on finding a new GP. He has 3 tips:

1. Find one close - if you're ill you don't want to travel far
2. Personal recommendation
3. Visit the premises – how does it feel?

These are all good points for me to follow. I tell him of my continued tiredness and ask for a certificate for 3 weeks. He gives me one for 6 weeks, saying "You'll need it". He's full of praise at the way I've handled things. "You certainly don't look like a chemotherapy patient" he says. I offer him my sincere thanks and we say our goodbye's.

18.08.2006

To St Thomas's for the "end of treatment scan". Strangely, the letter notifying me of the appointment is in green and without an "NHS" heading. Nonetheless it goes off without a hitch. Back on the 24th for the results.

I want to check if I need a blood test in advance of seeing Dr Beaney next week. Vicky in the Chemotherapy tells me I do, so I'll call in at 11.00 first. I also hand her my change of address details. She immediately hands them to the receptionist and she immediately calls up the "system" to make the change. There is an atmosphere of order here that gives me confidence after the bedlam of Harley St.

I tell her of my continued tiredness. She is unconcerned and puts this down to the very slow release of the Temozolomide. I'm happy with this explanation.

24.08.2006 - Results of the scan and Good News

I'm still very tired and needing my afternoon (or even morning) nap and so I return bracing myself for bad news. In any case, I'm determined not to blink. First it's a blood test. Seems to be a new team in the unit. A male nurse notes my fast track card and tells me to take a seat and he'll call me. It's a slowish turnaround but when "my" booth comes free another patient is ushered in. A patient jumps up and remonstrates that there is a "Fast Track" patient waiting i.e. me! A nurse quickly sets up an impromptu booth and another painless (almost) blood test follows.

Back to the Chemotherapy Unit where I bump into Rachel. "The results are **"Fab, absolutely fantastic everything has improved."** This is great news and when I later see Dr Beaney his more measured analysis is **"Excellent, couldn't be better. There is no sign of an active disease"**, He explains that a scar remains as scar tissue but this is the case for any wound. Wounds heal, but a scar will always remain - it's not a problem. There is **"no clinical or radiological disease"**. He wants to show me the scans on a PC, before seeing them explains that he is looking for a clear and sharp division between the left and right hand side of the brain. The first scan, taken in January, shows what to my untrained, eye, is a mess. Scan 2, taken last week shows a brain sharply divided into left and right - plenty of people don't have a division so sharp.

There is a little circle on the left but this is the scar he mentioned.

Having given me the good news from the scan, he then puts me through tests to check my reactions, eyesight still poor - I should get them tested but no panic.

Looking to the future, he says we must remain vigilant but they have “the processes in place to nip anything in the bud”. With this in mind he asks if I have seen Dr Costello. I tell him no, but had mistakenly thought that this was what the meeting on 02.02.2006 was about. He will take this forward and I confirm I’m happy for future review meetings to be at London Bridge.

Spatial awareness and short term memory, being the sort of things they want to keep an eye on in the months and years ahead. “Yes, years”, he says, “That’s what we’re working to”. Excellent.

We talk about a return to work. “Yes” is the conclusion but very slowly, backing off if there is the slightest problem. I tell him of my continued tiredness but it is no surprise to him given the volume and power of the drugs I’ve taken. It could take several months before they’ve fully worked out of my system although a few more weeks should see some improvement. My present certificate expires on 11.09.2006 and he concurs that I can try a return after that, but just 1 day then 2 and build up from there. I sense, that like Dr Fish, he doesn’t trust me on this point. He does not want to lose his star patient on an ego trip!

The meeting ends with me helping out Dr Beaney by giving him the dates I was taking Temozolomide (taken from my notes). “Excellent. We now have a complete record of your treatment”, he says. I’m flattered my notes have such credibility. I’ve pushed the cure not care angle ever since the tumour was taken out and feel I can take some professional as well as personal satisfaction in my continued survival.

What is particularly striking about this news is the enthusiasm of the medical staff. When Dr Beaney showed me the scan it was so obvious that he was speaking with pride. Rachel is showing real enthusiasm and Vicky gives me a big hug. There is a feeling that the team has really achieved something. To me this adds credibility to the results.

I ring Lisa with the news - she is over the moon. I’ve put her through so much. Walking back I pass Ray’s office so call him and we celebrate with a medicinal bottle of Italian red. By the time I get home Lisa has booked a ferry to France. The following evening we celebrate in her favourite restaurant - after she drives some 600 miles!

11.09.2006 Dr Benson - my new GP

This is my first meeting with Dr Benson but he seems to have read up about me and whilst I am doing the talking, he is taking notes. I am tired and probably look it, so when I ask for a return to work certificate he looks horrified. I tell him that a limited and slow return is endorsed by Dr Beaney and he relents, giving me a certificate with the words “very gradual rehabilitation recommended”. He underlines “very”, telling me to start off with 1 day, avoiding the rush hour and build up from there. If I can’t get a seat on the train, wait for the next one he instructs. I’ll try!

The Comeback

13.09.2006 Back to work at The Royal Bank of Scotland

After 277 days off sick, I'm back at my desk in Waterhouse Square, Holborn. I caught the 7.36 to Cannon Street (sorry Doctor) but I heed his advice coming home. In any case, I have no choice; I'm wiped out by 2.30 and should have left then but struggle on until 3.30.

An interesting day. Bizarrely, the departments weekly communications meeting takes the form of a survival exercise. Train delays mean I miss a couple of bits of info but my team still finish second, a fitting tribute. I have a chat with Jon. He is comfortable with me building up but how can I be used? Coutts integration, Stockbrokers integration and RBS expansion in England & Wales are all mentioned but it depends on how quickly I recover. He will drop me an email next week.

Aside from starting to read 1,400 e mails, thank goodness I got someone to put an out of office notice on my e mail, my big achievement that day was remembering that the grey bin over there was for confidential re-cycling. I was rebuilding!

21.09.2006

Still nothing confirming my appointment for 09.10.2006. I leave a message on Rachel's voicemail asking her to ring me with the time of the appointment.

22.09.2006

I'm out on my daily walk when Rachel returns my call. The appointment is set for 6.20 p.m. on 09.10.2006. "It's going to be a late one that night" I say. So much for offering an improved service for private patients (Dr Chitnavis 02.02.2006). I'll take the appointment and ask for more convenient times in future.

"Do you need another scan?" she asks. I'm tempted to say "shouldn't you know" but instead tell her "no" as my last one was only on 18.08.2006 with the results given to me on 24.08.2006. She says I'll have one for my next meeting, which concurs with my expectations.

Later in the day I call Rachel again. We've been invited to a New Delhi wedding over New Year but I'll need some jabs, Dyphtheria of which I'll need next week. Given that my body is trying to get rid of drugs, is it OK to add some more? It should be but she wants to check, ringing back and leaving a message saying, go ahead subject to my GP being satisfied as to the state of my white blood cells (which have been a problem). In the end we decide not to go. The thought of spending c£2,000 now, only to find we have to cancel nearer the date, is not attractive. Anyway, we don't know them well.

23.09.2006

Following my conversation with Rachel yesterday, a letter arrives from SNS Associates confirming the 09.10.2006 appointment. I see "SNS" stands for Spine and Neuro surgery. The meeting is with three Neurosurgeons, including Dr Gullen - "whip it out" from February, a Neuro - Oncologist (Dr Beaney), a Neuropathologist and a Clinical Nurse Specialist (Rachel). I'm asked to bring along any scans and told I'll need to register on arrival.

I'm puzzled and a little concerned. My scans are at St Thomas's and Rachel should

know this. Why are there three surgeons at the meeting? The last scan showed just a scar and inert matter. The only way to get rid of the scar is to cut it out and create a bigger one!

I call Katherine Oliver, the signatory. The grouping is at the request of Dr Beaney (fair enough). I ask her to get the scans from Rachel and ask about the registration mentioned in the letter. Seems it's fire regulations and I'll have to do this every visit. So why do they want my insurance details again? It's because they've got a new computer, is the reply.

I will need to go well prepared. I don't want a repetition of Harley Street.

As I type this, a neurologist comes on the TV to comment on the progress of Richard Hammond, the "Top Gear" presenter that crashed at 300 mph. He is showing progress and humour. He comments that humour is very important in helping the brain recover. I couldn't agree more.

30.09.2006 - eye test

An eye test at Dolland & Aitchison in Tunbridge Wells. Although the view was that my eyes would regain their full strength i.e. weak, they've just got weaker. Or at least that's what I thought - they've actually got stronger, slightly, but they are recommending bifocals or varifocals (which will take a bit of getting used to). I opt for the latter - £512.50 please.

03.10.2006 - Tunbridge Wells move complete

We'd decided to move to Tunbridge Wells as part of our reaction to news of the cancer (02.09.2005). We'd moved to a small place back in July but today we've completed the move into what will be our permanent home. There's plenty to do, which we like, but importantly, it's in the catchment area of the best primary school in the area. This gives Lisa the necessary support and comfort that Lauren is on the path to a good education.

09.10.2006 London Bridge Hospital - SNS Associates and a Maserati moment!

Drs Beaney, Chitnavis, Gullen and Rachel MacArthur greet me. I'm able to give a positive answer to the usual questions. I mention my eyesight difficulties and confirm the expectancy is that new specs will restore them. There is a chat around the screen on the scans progression - I like Dr Beaney's comment that I am the "Gold Standard". The risk, indeed probability, is that the cancer will return, so a scan in advance of our December meeting would be prudent. Dr Beaney will arrange. For the time being, go away and keep fit. It could take months for the tiredness to go away.

He adds that Retirement is something to consider but in the meantime, ensure my return to work is slow - don't attempt to overdo it.

Rachel asks me to take away the scans as my filing system is probably better than theirs. On getting home, I see what she means. I make a start by putting them in date order and giving them their own folders, but what should I find with the 20.09.2005 analysis notes but a copy of the January/February edition of the Maserati Owners Club bulletin! I'd be worried if it had been the Mazda Owners Club - at least a Maserati suggests I'm being dealt with by successful people with flair, operating at the top of their game!

12.10.2006 – RBS Occupational Health comment

Back at the office Jon tells me Occupational Health is happy with my previously agreed 'comeback' timetable of 1 day a week for 2 weeks, 2 days but not consecutive for 2

weeks, 2 consecutive days for 2 weeks, 3 days but a break between day 2 and 3, and so on, building up to 5 days during January.

I will continue to try to avoid rush hour trains in accordance with my GP's instructions - well at least at night.

28.10.2006 - Pick up my new specs.

My Varifocal specs have arrived and they are great. I'm given a chart with 8 paragraphs of text on it and start reading the 8th and smallest one. The expectancy was that I would only get to the 6th smallest! I was told that it may take 2 or 3 weeks to get used to them, and for some people, never. It takes me 3 minutes. Good things are easy, it's bad news that takes time. I walk home, but as a precaution, take the route with least busy road crossings. Next day it's off to France for a short break.

03.11.2006 Dr Benson

Despite last week in France, I'm still unable to shake off this cough. It's on the cusp of going but then comes back at its full strength again. Off to Dr Benson, my GP. He gives me a stethoscope examination and prescribes a weeks supply of Penicillin.

21.11.2006 - another scan

Back to St Thomas's for another scan, the results of which I will get on 11.12.2006. First of all I pop down to Oncology to see Rachel. I want to give her my previous scans for comparative analysis. I do not want to get to London Bridge only to find this is the first time they are looked at.

Rachel is not there but I see Vicky who tells me how well I look. I tell her of my inability to get rid of a cough, but on confirming that the phlegm is not green, is happy. I've got nasty scabs on my scalp and she agrees with my analysis that the problem is down to me not treating my new baby soft hair appropriately. On hearing I'm to have a flu jab, she gives me a blood test. I'm to call tomorrow for the results but she will fax the results over to my GP to obviate the need for this weeks Phenytoin tests. I do like her proactiveness.

Over to the MRI unit for the scan. I fill up a private patient form and a wait, post scan, of just 5 minutes and I'm given the actual scans. Back down to Vicky in Oncology who takes them and the previous ones. She will personally give them to Dr Beaney. Thanks Vicky.

22.11.2006

At home today and the phone rings. It's Dr Beaney. Things are looking good. "I'm struggling to find anything" he says. I assume he means "anything wrong"! He's very pleased and we will discuss them at the SNS Associates meeting in December.

A few minutes later Vicky calls to check that Dr Beaney has called! This is good service. She also gives me the results of my blood test. My platelets are now at a record level (for me) of 219. I thank her for her efforts on my behalf and arrange to pick up the scans (although she helpfully offered to look after them) on 01.12.2006.

Although at home today, I consider myself to be working. I've now built up to 3 days working in London with my day's at home spent "working" to get fit. This involves long disciplined walks (no gazing in shop windows) in the mornings and a lie down in bed for a proper sleep in the afternoon.

01.12.2006

To St Thomas” to pick up my scans from Vicky. She also gives me a printed copy of the analysis and a schedule of my blood test results. The scan analysis was done by Dr Naomi Sibtain. Not heard of her before but the paper shows that they were compared with the 18.8.2006 results - just what I wanted. There’s a lot of medical jargon I’ll need explained to me on 11.12.2006 but phrases like “less conspicuous” and “a reduction in the size of the nodular enhancement”, look encouraging. I’ll also be able to ask about the significance of the FBC categories that carry a “!” warning.

11.12.2006 London Bridge Hospital - SNS Associates

I see Dr Beaney and Dr Chitnavis at 6.50pm. Rachel is also there and Dr Gullen pops in near the end to shake my hand and tell me I’m looking well. I don’t expect a bill for that piece of analysis!

I pass over the scans and copies of Dr Sibtain’s notes. Dr Beaney tells me that I’ve clearly joined a very small group of patients that is going to survive longer than the norm. He’s frank in telling me that it is almost certain that the tumour will return but hopefully, we are looking for a year without symptoms.

As to how we tackle the future, it’s going to be regular scans, with the next in 2 months. He wants to take action, long before any symptoms develop, he says, giving a sideways glance to Dr Chitnavis. I assume this glance means that “action” = surgery! I go back to my self motivating point of 40 years ago we still had not had the world’s first heart transplant yet now it’s almost routine - certainly less complex than the operation I went through. (*Note: World’s first heart transplant: Cape Town, South Africa 03.12.1967. The UK’s first successful heart transplant was only in 1979*). As for next steps, it’s a session with Dr Costello, a neuropsychologist at Kings, to test my memory etc. This is the meeting that was meant to take place in January last year (see notes with Dr Chitnavis 02.02.2006).

As a passing comment I enquire as to the Maserati owner amongst us (see 09.10.2006), brandishing a file with the scan application, analysis and Maserati newsletter. Turn’s out it’s no one in the room, but that Dr So n’so is probably the culprit. No matter, it’s just me being wicked i.e. back to my normal self. I leave, allowing myself a little grin.

12.01.2007 Dr Benson

I can’t get rid of this cough and its making me lose still more weight! Back to Dr Benson for a solution. A thorough going over with the Stethoscope reveals nothing of concern. He feels I’m just at the tail end of a virus. However, “let’s deal with this scientifically” he says, sending me off for an urgent Chest scan at Pembury hospital and wanting me back on Tuesday for a full blood test.

Over to Pembury, where I’m seen instantly - what a service. It will be a couple of weeks before the results are back with Dr Benson.

14.01.2007

To Clanricarde Medical Centre for a blood test. It’s good this place. Everything is done more or less on schedule - I just feel comfortable.

21.01.2007

Katherine Olliver at SNS Associates had called Lisa regarding the appointment / was trying to arrange - I think she means follow up on the action points from my last

meeting on 11.12.2006!

A letter is on its way and she tells me the appointment is set for 12.02.2007. I'm in Spain and ask for an appointment in the following week. No, SNS Associates only meet once a month. I tell her not to bother. I'll follow up with Dr Beaney via St Thomas's. What a waste of space this lot is. Get me back to St Thomas" and Dr Beaney.

22.01.2007 - Dr Benson calls

It's the results of my chest scan. I've a slight chest infection and Pembury want to repeat the exercise in four weeks. Dr Benson offers me medicine but I tell him I've improved a lot and think the Benylin will sort it. He's comfortable with this and asks me to call in a few weeks for another examination and fix up another scan appointment. He's happy for this to be left until after my break in Spain.

05.02.2007 — Dr Costello at Kings College

Not the best of starts to the day. Having caught a virus off Lauren (it had worked its way through Lisa a couple of days earlier), 4.30 am see's me with my head down the toilet. Not the best of preparations for what is billed as 2 to 3 hours of tests. You try reciting a 6 figure number backwards as you swallow hard and reach for a carrier bag you've stuffed in your pocket!

Overall I go away a little down as I know I could have done better. Some I sail through and others, well I was never able to do a Rubik cube anyway. A number of tests were impacted by me concentrating on not throwing up! Dr Costello tells me the test could be repeated later if need be, but at this point I don't see the value. I later get a copy letter from Dr Costello to Dr Beaney outlining the results. I'll discuss with him at our next meeting, although the reference to "Executive tests" suggest they were trying to stretch me - I'm good at those ones.

09.02.2007 - Scan at St Thomas's

The usual scan. Now, off to Spain for some vitamin D. Dr Beaney will call me with the results on my return.

15.02.2007 - Phone call from Dr Beaney

"Excellent, everything stable, if anything, there is a reduction in Brightness" he tells me. Top results. It means I've had two scans that have improved on a base line of "**Excellent, couldn't be better. There is no sign of an active disease**" (18.08.2006). I tell him of my chances of redundancy and early retirement. "Grab it" he says. I explain my intention to take the summer off and go freelance in September. "Am I being silly?" I ask. "Not at all" he opines. Good news!

28.03.2007 - House of Commons

Through the Hammer Out brain tumour website I find March is Brain Tumour awareness month. Here I am back at my old haunts of the House of Commons, lobbying my MP. I meet the organisers beforehand and am asked if it would be possible for me to go along and address the all party Brain Tumour group of MP's afterwards? No problems. John Bercow chairs the meeting and my theme of moving from Care to Cure is enthusiastically cheered. I push my line of the advances made in the last 30 years in heart transplants - now almost routine, and how we must replicate

this for brain tumours.

It feels great to be back at the House of Commons with a chance encounter with Lembit Opik (“Cheeky boy”), reducing me to a fit of laughter.

01.04.2007 - Photo opportunity

My press release of the House of Commons lobby and subsequent telephone interview with the Kent Messenger brings a photographer to our home. It's a lovely photo of the three of us but having a cute little girl was the catalyst for a colour photo and half a page of coverage! Cancer patients are two a penny but when the reporter heard a little voice in the background, well that's a human interest story! That afternoon we celebrate, with a wine tasting party, Lisa's 40th (yesterday) and my 50th (tomorrow). One in the eye for the statisticians!

09.05.2007

Over the past couple of weeks I've been chasing for the date of my scan. Feedback is set for 14.05.2007 at 6.20p.m but I'm still chasing for the date of the scan. Jo, from the scanning unit in London Bridge rings telling me they can't do it before 18.05.2007 - little point in having the feedback meeting on 14th then. In talking further it would seem they are unable to inject me to enhance the image, therefore the scan would have to be done at St Thomas's. A call to Vicky who tells me they can. I ring Katharine Oliver (an acrimonious discussion) and leave a message for Dr Beaney's secretary to call.

15.05.2007 - Scan at St Thomas's

I'm back at St Thomas's for my scan. It was meant to be at London Bridge on 14.05.07 but a feedback appointment was arranged but no scan. Vicky and Dr Beaney sorted it out and I'm glad to be back. I'm early and to save time the nurse puts in the needle pre-scan - like a socket. OUCH and DOUBLE OUCH when she takes it out. I feel a wimp but her apologies suggest she feels she could have done better! She praises me for keeping still. All I need now are the results. She will make sure they are ready for my meeting with Dr Beaney on 24.05.07. Hopefully Vicky will tip me off before.

18.05.2007 - last day in the office

Whilst I've built up to 4 days a week, the opportunity to take early retirement with a redundancy package and then spend a long summer in France completing my recovery is too good an opportunity to miss. After a lunch time session I bid my farewells. I'm deeply moved by the comments made about me - I try not to show it, but I am. Royal Bank of Scotland has been great and my fight was respected by more than I imagined. Thanks everyone.

On the health front, another benchmark reached. Having got back last September with my belt on its final notch, I leave with it firmly on slot 3. Still a little to go but at least a comedy sketch in public should be avoided.

24.05.2007 - Scan results

Dr Beaney is off this week but Vicky calls with the scan results. It's no change, which is just what they want. The image shows the effects of the radiotherapy, which will always be there. Bottom line is, I'm still in there! As we are booked for a summer in France with friends joining us, I tell her I felt it was inevitable this scan would take a turn for the worse! She laughs and tells me not to worry. I tell her I would like to see Dr Beaney

before I depart on 10.07.2007 and she will fix this up.

07.06.2007 - St Thomas's and Dr Beaney

Vicky called last Tuesday as we travelled back from Scotland and the confirmation letter has come through for a 2.30 appointment (I thought we'd agreed 11.00 but 2.30 is better). In any case, it's 3.00 by the time I see Dr Beaney. It's a very relaxed meeting as "things could not be better", he tells me. We talk of the future, and here, the plan is to keep a close eye on me so if anything goes wrong, the medical team can react quickly. I'm not to be worried about the continued tiredness - it will take months before I'm back. Nor should I be concerned about the slight twitching in my right leg (I do an exaggerated demo). As for my issue of the moment, Hay Fever, it's ok to take the occasional tablet. Thank goodness. I'm comforted that by now, my worries centre on the availability of a clean hanky! He suggests keeping me at St Thomas's. I heartily agree. It just wasn't working at London Bridge.

Things to look out for are headaches and deterioration in my spatial awareness. I mention what I consider to be a relatively poor performance when I saw Dr Costello, but the results didn't cause him any worry and to hear me say I could have done better is encouraging. My illness that day was down to the punishment my immune system has taken. There may be a slight lasting damage in this area.

He was aware that I was likely to be leaving the RBSG but I add I'll continue with private healthcare - "that will be useful".

I mention my visit to the House of Commons and likely attendance at the Brain Tumour UK conference. It seems he was a past speaker at the conference.

I leave having given him my thanks for everything he has achieved and with a copy of the Kent Messenger article. He agrees with my opinion of the media - "cancer patients are two a penny but a cancer patient with a cute 4 year old, well that's a human interest story worthy of half a page and a colour photo!"

Our next meeting will be post France on 30 August (*later changed to the 23rd*) providing the scan can be done the week before. It is, a letter swiftly arrives for 16 August at 4.00. Thanks Vicky.

I'd asked Dr Beaney what I, or more likely Lisa, should tell medics if I have a relapse whilst in France. A few days later a letter arrives from Dr Beaney. It outlines my treatment cycle and concludes with the reassuring statement that the last "MRI scan showed no evidence of an active tumour". Fingers crossed I don't need to use this letter.

02 & 03.07.2007 - Brain Tumour UK conference Nottingham

Held at the University. It's an interesting experience and I find myself doing a lot of talking at the high grade glioma patient's session (not surprising, I suppose). There is more going on than I realised but the stats for the post 2 year survival are not encouraging, with 5 year survival rates described as "virtually unheard of". I leave, a little down but soon pull myself together. "Virtually unheard of" means it has been heard of, just not all that often. Well prepared to be bored.

16.08.2007 - Scan at St Thomas's

Now back from France, Dr Beaney's letter stayed in its envelope but a bizarre kitchen accident to my thumb results in 4 visits to the hospital, via a GP and English estate agent! Lisa has handled worse news and laughs as the nurse tells her "it's a man's

injury, a lot of blood but no lasting damage”. On our final visit I’m handed a form on departure to claim back the €1 parking fee as we’ d only been there 20 minutes – we didn’t bother!

24 hours after 5 weeks in France, it’s back to the old routine and a scan at St Thomas’s. I wish they would go back to the old way of injecting the dye when they need to, not have me sitting/lying there for 20 minutes with a needle in my arm. I think this sort of injection is a Cannula - the type they have when changing drip bags over.

23.08.2007 - The scan results

To Dr Beaney and Vicky. It’s another great result with no change, just as he would want. I’ve been scanned every 2 or 3 months but this time, Dr Beaney is happy to leave it for four months. Vicky to arrange. I tell him of my intention to look for employment, either part time or short term contracts. He is content with this, but don’t overdo it. He tells me that he has just become Treasurer of the British Neuro Oncology Society in Edinburgh. They bank with RBS in Edinburgh and he is having difficulty in transferring the account to the Haymarket. I think I convince him that it’s unnecessary to make such a transfer but Vicky is looking at him with daggers, he says. Fancy troubling our star patient with such trivia! It’s a relaxed meeting and I thank them again for all their efforts. Fingers crossed for the future.

03.09.2007 - Back at The Royal Bank of Scotland

I’m back at RBS as a sort of temp, thanks to my old mate Dave Wiggins. Money’s not great but it gets me back into the swing of things and after a couple of days I find I’m enjoying it and adding value. I’m only doing 4 days a week but that’s my choice. I can do 5 or 3 days if I want, it’s down to me.

At least the belt index is looking good. My return last September saw it on the final notch. By the time of my May departure I was on notch 3. My latest return sees me on notch 4. Still no worries on the obesity front.

04.09.2007 - Laurens first day at school

A milestone. I’m still here to be with Lisa as we walk Lauren to her first day at Claremont Primary School. It’s a good feeling.

12.11.2007

Vicky rings to check my scan has been booked. It has and we agree a feedback date at St Thomas’s of 06.12.2007. I tell her I’m doing well but she counsels me against working too hard. She asks if I would be interested in speaking to a Market research firm on behalf of a pharmaceutical company. I would, and she will arrange for them to get in touch.

It’s Astra Zeneca - They want to meet medics, patients and carers. Whilst not having an NHS “carer”, my wife did a lot of caring and her views would be worthy of interview. I give a run down of my treatment and recent engagements i.e. House of Commons, Brain Tumour UK, work etc. A 90 minute interview is booked for home on 19 November at 6.30 p.m. - a fee of £50 each!

19.11.2007 - Meeting with Astra Zeneca

Morgan Emyr, Brand Insight - RECENTIN, Global Marketing calls for a video'd meeting. A good start to the meeting with £100 put on the table. Thanks. He is looking at all aspects of cancer treatment and wanted to hear all about my treatment, warts and all.

In a wide ranging discussion what was striking for me was listening to my Carer, Lisa, explain what she went through that morning in August 2005. She is full of praise for the way staff kept her informed. It's the first time I've heard some of her comments and, boy, it was tough for her. She was so good at protecting me from what were dire predictions. At the conclusion I give him a copy of this Treatment Log (*the 1st edition of Survive and Thrive – my encounter with cancer*) inviting him to revert if he needs clarification on anything.

03.12.2007 - Brain Tumour Support Group St Thomas

Vicky had asked me to go along and speak to the group and one patient in particular. I'm introduced as their "star patient" and give a run down of what happened to me. Afterwards I speak to a lady that feels, her employer, a major City law firm, are putting pressure on her to return. I give her tips on handling a return to work but my basic message is get your GP behind you. xxxxxxx will think twice about the adverse publicity, making a woman with cancer redundant would generate. *Name of employer deleted to protect identity of the patient.*

04.12.2007 - Scan at St Thomas's

My previous two visits have seen them put the needle in my arm 20 minutes before I went into the scanning room, making movement difficult and painful. Why don't you just inject me when you need to whilst I'm on the MRI bed?

Before I'd been told it saved time but this time she agrees to give me the fluid injection whilst I'm on the scanning bed. Result!

06.12.2007 - The scan results.

Dr Beaney is off ill this week but Vicky calls with the result. It's another good one with absolutely no change. Great result. Pop in next week to see Dr Beaney if I want to, she'll give me a call next week. Later on, looking through my past notes, I see that on 11.12.2006, Dr Beaney, in telling me of the almost inevitability of the tumour returning said "hopefully we are looking for a year without symptoms" - almost there.

05.01.2008 - Another Comeback appearance

It's a friends birthday party at Qualingo's in St James. Lisa is looking stunning but how do I look? A number of people attending will not have seen me since the Saturday before I started Radiotherapy/Chemotherapy, that would make it 01.10.2005.

Expectations then were low and sympathy high, but now? I'm looking a heck off a lot better is the answer. All I need do now is keep it up.

23.01.2008

Lisa has found some sunny climes for us at the half term break. To prevent the inevitable clash, I leave a message with Vicky asking for the scan to avoid the w/c 18.02.2008. Vicky calls. Dr Beaney is happy for the scan to wait until late March, c4 months since the last one and 31 months since they cut me open. Fingers to remain

firmly crossed. Just get on with life.

30.01.2008 - Scan notice

A letter arrives with a scan date of 12 February at 12 .30. I'd expected it to be end March but I'm not unhappy with this earlier date. I've been feeling tired recently, again on the cusp of a cold, so if there is anything amiss, let's find out and deal with it.

12.02.2008 - 10th post op MRI Scan

Arrive at 12.55. I'd been able to get the appointment put back an hour. Important when you're on an hourly rate. They've got a backlog but I'm seen shortly after 2.00. Needle hurt a bit today, both going in and coming out. Still, this is a small point. I've always been concerned that I may have moved and that the analysis is done on an inaccurate picture. But no, I'm being paranoid and when I ask, am told, as usual, that I was perfectly still. They'll get the results over to Vicky by Thursday.

14.02.2008 - scan feedback

08.55 and it's Vicky calling with the scan results - it's another no change! Brilliant. Lisa can now get on and book our half term trip away. Make it a luxury one is Vicky's advice. She'll fix up an appointment for me with Dr Beaney.

Lisa lets celebrate. I'm still surviving and the family is thriving. Text message from Lisa: "Lanzarote 3 nts from Monday. Booked!" That's my girl.

01.04.2008 - My views to the Cancer Czar

As part of a national review of follow-up care requested by Professor Mike Richards ("the Cancer Czar") I go along to a meeting, run by the Picker Institute, in the Holiday Inn Bloomsbury. It's all part of the new Cancer Reform Strategy. I'm the sole Brain Tumour patient in a group of 8 and give my views on follow up care. I seem to be doing a lot of talking. Surviving beyond expectations and putting something back, gives me a glow.

18.04.2008

Rachel calls. Dr Beaney wants to put off my next scan until June but if I have any problems just call him or Vicky. I'm happy with this. My stamina is still not fully back and this extra gap between scans may be just what I need. She will leave it a few weeks before booking me in as a booking now would generate an appointment in a few days - that explains why my last appointment was earlier than expected. 10 more days and I'll be 32 months post op!

28.04.2008 - 32 months post op

32 months and I'm still here. A letter arrives with the next scan booked for 12.06.2008. Fingers crossed but feeling good.

12.06.2008 - 11th post op MRI Scan - a change in NHS rules?

To St Thomas's for the usual MRI scan. Now await the results.

I've been reading a lot about NHS rules denying treatment to patients that can afford a drug, unless they pay for their entire treatment i.e. scans, side effect drugs, blood tests etc. Looking back, clearly my confrontation on 20.09.2005 and attempts to move me to London Bridge (02.09.2006), were about this. It would seem that my treatment ran contrary to NHS rules - I just forced my way to the best treatment! Word in the press is

that this bit of socialist dogma is heading to the dustbin of history, not before time.

19.06.2008 - The Scan results

I haven't seen Dr Beaney since August. Vicky tipped me off a couple of days earlier that it was another clean scan, so the "star patient" hasn't let the side down. Vicky hands me a copy of the scan analysis notes. The word "unchanged" is prominent and finishes with "CONCLUSION: stable appearances". I couldn't ask for a better result. My stamina is not completely back, but it's steadily rising and recently I've been working 5 days. It's not at the same intensity of pre op days but I feel I can push the boundaries a bit more.

He is very pleased with me and after a few eye and co-ordination tests, tells me to see him again in 3 months but with the scan put off for 6 months. The longest scan interval so far. He tells me to stay active and any problems, just call.

This is a tremendous result with the confidence behind a 6 month scan interval giving me an added boost. I offer my thanks again and depart for home, firmly on schedule to warn off any of Lauren's predatory boyfriends!

08.12.2008 -12th post op MRI scan

To St Thomas's for the by now familiar MRI scan. Now await the results.

11.12.2008 - Scan results

To Dr Beaney and the early Christmas present of hearing that it's another "No Change". After some eye and co-ordination tests it's decided the next scan can wait 6 months with an appointment with Dr Beaney in three months.

12.03.2009 - Dr Beaney

One of the things Dr Beaney told me to look out for was any deterioration in my spatial awareness. I'm sure it was nothing but let me raise it just in case. I have a fast paced walk but a month back, whilst walking to work, I tripped on the pavement and found myself face down on the road. Was this just a trip on wet uneven pavement, which could happen to anyone, or was it the start of something bad? "Those scans see everything. Let's look at that scan (08.12.2009) again" says Dr Beaney. I can hear a couple of other people have joined Dr Beaney next door. I speculate to myself if in looking for tumour growth in December, had they lost sight of something going wrong elsewhere? I don't have to wait long with Dr Beaney returning with the news of "that scan could not have been better". That trip was just one of those things. I'll see him again in June and will have a scan a few days before.

08.06.2009 The 13th post op MRI scan

Back to St Thomas's for my 13th post op scan, originally booked for 13.09.2009. I got married on the 13th so this number only has good omens for me; however the appointment was 2 days after I was to get my feedback! I speak to the MRI team who helpfully changed things to today. As usual it goes smoothly, with the fluid injection done whilst lying on the scanner - good.

11.06.2009 - The Scan results

You can always think of a reason why this scan could be a bad one. In truth, you cannot tell - these machines are meant to spot things before it is obvious to you. Besides, none of things I've been told to look out for have materialised, so fingers

crossed. A cheery welcome from Vicky suggests it's not bad news and indeed it's not. After putting me through some hand/eye coordination tests, Dr Beaney again tells me "that scan could not have been better". I'm spending August in France and will see Dr Beaney again on 03 September. The next scan can wait until December.

03.09.2009

To Dr Beaney for my regular check up. He is without any assistance today and there is a backlog. I find myself talking to a patient with a Zimmer frame. My conversation turns unintentionally into a motivational talk. I sense other patients listening in.

When I get to see Dr Beaney he puts me through the usual tests, reminding me of his analysis of the last scan that it could not have been better. The next scan will be as scheduled in December and I'll have a blood test done to check all is ok.

After my appointment I go over to the patient I was talking with to say cheerio and best of luck. His wife looks up to me and almost tearfully says "thank you, thank you". I'm slightly embarrassed, but if my good fortune can encourage others, so be it.

23.10.2009 - my proactive GP

Lauren and I have both had a cold for a couple of weeks. Something is going around the school and some 20% are off. Yesterday evening should have seen us arrive in Spain for a short break but she was too poorly to travel. Lisa calls our GP who prescribes a small dosage of Tamiflu. I'm at work but I'm coughing so much it's impossible for anyone to have a phone conversation. I set off home, finding a message on my mobile from Dr Benson. Having diagnosed Lauren, he wants me to go on Tamiflu as well. That's proactive thinking. A few days pass and we both recover but thanks Dr Benson.

06.11.2009 - BT Buddies and a spooky moment for Lisa

I've been in touch with BT Buddies (www.Btbuddies.org.uk), a relatively new cancer charity but one that is dedicated to those with a High Grade Brain Tumour. It is excellent with a breadth and depth of information that I oh so wish was around back in those early days of diagnosis in 2005. Its web site is so easy to use.

As part of International Brain Tumour Awareness week they did a press release of me, The Kent & Sussex Courier call and after a lengthy conversation, send a photographer round. Roll on to publication day and Lisa is shopping at M & S. At the till, she looks up and sees a display of 15 editions of The Courier with a colour photo of her husband, occupying half the front page - scary! Inside there is another half page and a nice photo of the three of us.

The front page carried an attention grabbing line of "I refused to accept my death penalty". I didn't use those words, but if your business is selling newspapers, I accept a quote along the lines of "I always refused to accept the inevitability of those projections" needs massaging! Importantly, the issue of Brain Tumours was raised.

The following days were astonishing with people stopping me in the street and on the train. For those that had a sick relative, I could offer myself as evidence that stats were there to be beaten.

27.11.2009 - Another Scan

Back to St Thomas's. One of the scanners is out, so they have a backlog. I'm under pressure (quite a lot) to reschedule but with feedback booked for 03.12.2009, that's not possible. My appointment is only delayed an hour but to "save time" they put the

needle in my arm ready for the enhancing fluid whilst I'm sitting outside. Why do they do this? Perhaps it saves 5 minutes, collectively not enough to see another patient through, but it's uncomfortable, indeed painful when the nurse bumps into you. At the end, the attachment is simply thrown away. So cut costs and improve the customer experience by injecting the fluid once the patient is on the scanner. Moan over, the scan goes ahead and I've kept perfectly still.

Later I go for that blood test Dr Beaney wanted from our September meeting. I don't know how they do it, but the blood tests at St Thomas's are always painless.

03.12.2009 - The scan results

To Dr Beaney and Vicky for the results. First the coordination tests. No problems, as for the scan, again no problems He is supportive of my desire to step up the pace once my current assignment expires. Just be sensible. Next appointment 03.06.2010 with a scan a few days before. This was an important one for me. At work I knew I was going to be needed for at least another 3 months (*it turned out to be another 42 months*). I'd seen an expensive bracelet I wanted to buy Lisa for Christmas. but, if this scan was a bad one the bracelet would look too much like a goodbye present. I'd held back buying it until the results were in. Now back to the jewellers and splash the cash.

07.02.2010 - Appearance at the Hammer Out annual conference

Yet to happen, but I've accepted an invitation to be a speaker at the Hammer Out Brain Tumours annual conference. I'm really honoured at receiving this invitation. Hammer Out is west country based but the "Your Story" page of its website:

www.hammerout.co.uk allows anyone to put their experiences down. I've put three entries on over the last couple of years and by adding my email address have had many e mails from those in a less fortunate position. I hope I've been able to offer encouragement. It's a privilege to be invited and hope to meet many of you.

17.03.2010 - Hammerout conference, Exeter

I'm the patient speaker Sunday morning. Arrive Saturday afternoon and spend the rest of the day in meetings. Inevitably I'm doing a lot of talking but when I mention Dr Beaney's tip of 3 glasses of red wine, particularly Chilean with its high level of flavonoids, a brooding nurse declares "that has been thoroughly discredited". I'm not here to argue with disgruntled NHS employees and let it pass.

Next day the first speaker is having problems loading his presentation and I'm straight on stage, wired up with a roving mic and a lectern for me to place my notorious "No cure" benefit patient consent form (08.09.2005) and the Maserati Owners club bulletin I'd found in my scan folder (09.10.2006), always guaranteed to get a (horrified) laugh.

I'd done a fair bit of public speaking and with an audience of more than 100 patients/carers knew a strong performance would be motivational. I felt I'd delivered that performance, confirmed when an old lady came up to me at the end saying, "you were wonderful, you should be on the telly, I'm going to write to BBC South West". My real reward came the following Saturday morning. Still in bed when the phone went. Lisa quickly sensed the nature of the call and left me in private with the caller "you spoke to me last weekend. I was just ringing to thank you for saving my life". Before I could say anything he went on "you've given me such hope. I did what you said and

went back to the hospital and they are going to look again next week to see if the tumour can be removed." Thank you, thank you". Phew, motivation and hope I can do, but cure.... I remember talking to him. he'd been told some months earlier they could do no more. However, here he was, admittedly frail, standing in front of me. That prognosis seemed hasty in view of his continued longevity, I suggested he went back and challenged them. He had received support from Hammerout but no one in the NHS was following up with him. I wished him all the best, grateful to be alone in the room when I put the phone down. I never shed a tear over my misfortune but I needed some moments alone after this call.

March & April 2010 Cataract operations

A routine eye check sees me referred to the eye clinic at St Thomas' by now a centre of excellence in my restoration. In a not uncommon consequence of the treatment, the Radiotherapy has caused some clouding and I will need to have cataract operations on both eyes. 18.03.2010, the right eye and back to St Thomas'a month later for the left. WOW, those ops are brilliant, my eyesight has not been this good since infants school. Not all operations are rescue jobs; these cataract ops are sheer improvement.

15.06.2010 MRI scan at St Thomas's

My 15th MRI scan. I arrive early and find myself talking to a distraught patient. I hope I was able to give some comfort. Now await the results.

24.06.2010 - Dr Beaney and the scan results

Another good one with "unchanged appearances". A number of hand/eye coordination tests are passed without problem.

28.11.2010 - MRI scan at St Thomas's

Not sure what happened here. I arrive for my usual scan but am told its booked for Guy's. I had two letters. On checking that letter did say Guy's, I'd missed that but the more recent second letter states the appointment is here at St Thomas' adding that the follow up with Dr Beaney is next Thursday - usually confirmed in a separate letter. After a short wait, a window is found.

02.12.2010 - Dr Beaney and the scan results

The scan showed no change and after the usual psychometric tests its carry on the good work, another scan in six months, no worries for Christmas.

18.02.2011 - St George's, UCL - lecture on patient messages

I'd been invited to do a lecture on the patient experience to medical students studying for an Msc in Rehabilitation. I enjoyed the afternoon and was getting good feedback. The lecturer sent me a copy of the feedback. I'm taken aback by the comments - you can still put on a show Dave. What I was really pleased about were comments like "really affected how I communicate", "made me reflect on my communication" " demonstrated how our documents and comments can be insensitive", result! That's 12 medics that will think twice. Count me in for the next crop of students.

14.06.2011- St Thomas's and an MRI scan

A bit busy today and put the needle for the injection to enhance the image in whilst I'm waiting outside. I hate it when they do that. Either I bump into something or someone bumps into me. Nothing happens today so lets just wait for next weeks results.

23.06.2011 - Dr Beaney and the scan results

A bit of a scare. I'm invited to come into a room to view the scans on screen. Why do I want to see them on screen, what's wrong? Nothing, he just wanted to shown me how good they were with no changes from the previous. Phew! I mention my stamina. Since the end of treatment this has steadily improved but of late I've sensed that it's peaked. It's not a problem, just not at pre op days. With a sigh, Dr Beaney responds "you are six years older". Oh well, at least It's just the three gray hairs.

16.11.2011 - St Thomas's and MRI scan

As usual, arrive a little early, but they are behind. could I come back some other time? Well no, but I've no problem waiting. I hear that someone hasn't turned up and 15 minutes later I'm on the scanner. I make the point I'm seeing Dr Beaney next Thursday. They confirm everything will be ready in good time.

24.11.2011 - Dr Beaney and the scan results

Everything was ready in good time and everything is looking good I pass the usual psychometric tests without problem.

26.01.2012- St George's, UCL - lecture on patient messages

This is the second year I've given this lecture to medics doing an MSc on Rehabilitation Services. I'm the "expert patient", giving a talk on the way messages are conveyed to patients - plenty of room for improvement. The talk seems to go down well with acknowledgement that things can be better. I feel I'm reforming the NHS, a dozen at a time.

20.06.2012 - St Thomas's and an MRI scan

To St Thomas's and the usual scan. The nurse recognises me. I should get a loyalty card.

28.06.2012 - Dr Beaney and the scan results

I arrive early and a nurse directs a patient and his wife to sit next to me. I sense this was deliberate. He was not in a good shape and I find I'm doing a motivational chat, which seems to give his wife a lift. Then, in to see Dr Beaney, it's another clear scan and I leave after satisfactorily performing the usual psychometric tests. Keep up the 6 monthly scans but make the next one November so as to keep the feedback away from Christmas!

06.09.2012 - a double check

I'd taken a few tumbles over the past few months. The sort of thing that could happen to anyone, but they'd happened to me. Could this be a sign of things turning? Dr

Beaney thinks it unlikely, but an MRI scan is the best way to check. Results come back and it's all clear. As a double check a review has been done on all the scans taken since 2006. In looking to see if a tumour was re-emerging had they missed something going on elsewhere? Absolutely not! I'm being well looked after here; now come on Dave, those cataract ops radically improved your eyes, use them!

08.11.2012 - MRI scan at St Thomas'

Notwithstanding the double check scan, we keep up the mid year/end year scan cycle with my 21st post op scan.

15.11.2012 - Dr Beaney and the scan results

A couple of visiting U.S Neuro consultants are present. Dr Beaney tells them "it's not just Mr Grant's longevity". Turning to me to say "the results were perfect, absolutely nothing wrong", turning back to the visitors "he's caring for his family, working full time, lobbying at Westminster or wherever he can, giving lectures, supporting others." On telling them that the part of RBS I was in had been sold off to 2 U.S venture capitalists, Bain Capital and "Bain" stammers one of them. The meeting goes on with the conclusion that we will stick to the 6 monthly scan schedule. As we leave I hear one of the Americans turn to the other and say "How?" We'll that's what the little ol Limey Health Service can achieve.

31.12.2012 - Team Top Performer

The year ends with me as the Teams top performer. Working with a portfolio of customers to ensure their processes and systems meet required security standards, my level of compliance was sufficient to lift the entire team over externally imposed thresholds. The result being that my employer, Worldpay, avoided a substantial fine. Augurs well for bonus time but more importantly, I'd proved to myself I was back at the top of my game. Whilst the job does not carry anything like the pressure or responsibility of earlier assignments, measured against externally set targets, I'd proved to be the best. It felt good. You can still hack it Dave.

30.01.2013 – A surprise “offer”

Tim calls me in. it's not fully signed off yet but if I resigned and found a job with a charity, Worldpay would pay my travel expenses and provided it was a big charity, make a donation to the charity. Would I be interested? Let me think about it and come back. My first thoughts were that it sounded too costly for me. After thinking about it overnight I revert to Tim declining the offer.

11.02.2013 - Go home Top Performer

It's 09.05. I'm summoned to a meeting with a senior manager and HR. No reflection on my performance (difficult one to argue) but I'm to go home and await an appointment with an Occupational Therapist in c2 weeks. It will take a further 2 weeks for the report to be compiled and Worldpay to consider its implications. I'm escorted out of the office, refused permission to talk to colleagues. Are they trying to get rid of me because I'm a long-term cancer survivor? Only a few days earlier I turned down an "offer" that in exchange for me resigning and finding a job with a charity, WorldPay would pay my

travel expenses and make a donation! Thinking about it, it was only last Thursday, whilst passing in the corridor he'd remarked "you turned down that offer didn't you?" "Yes" I'd replied as he carried on his way.

I may have had brain surgery but there's never been a suggestion that my negotiation skills were damaged.

15.02.2013 - St George's, UCL - Lecture on patient messages

The third year of medical students that I've lectured to and just like the previous years there is clear acknowledgement that things could be better and they personally will work to ensure such.

25.02.2013 - meeting with the Occupational Therapist

I found out the questions the OT would be asking and emailed a 2 page paper of my medical history. It's best to put things in writing - medics do get it wrong, and when dealing with one that is acting for your employer it is doubly important to get the facts straight.

I need not have worried. The meeting lasted barely 20 minutes. The Therapist seemed overwhelmed. With 21 clean MRI scans, what could he add? His "report" 'barely a page of text, went back to Worldpay, copied to myself, that afternoon. It concluded: "there is no medical reason why Mr Grant cannot return to work". However, the sting in the tale was confirmation that I, "was protected by the Equality Act 2010". Ouch! Still can't complain about a couple of weeks off. Business as usual on Monday - *I thought*.

Macmillan Cancer Support and the Equality Act 2010

After seeing the Worldpay Occupational therapist I headed to the Dimpleby office at St Thomas' to get up to speed with the Equality Act. *Macmillan produce an excellent publication on the Equality Act for employers. It defines their responsibilities to staff with a cancer diagnosis and provides templates and DVDs to assist an employer in embedding the Act into its processes.* I bump into a nurse. "What are you doing here David, Dr Beaney is not in today?" I explain, astonished as she says "oh it's Americans that own your company. Do you remember those two Americans at your last meeting? They were going on and on about them. They said there was "no way they knew you were a long term cancer survivor". Seems the "how?" at the November meeting was about my longevity as an employee rather than patient!

26.03.2013 - Brain Tumour Information Day, Kensington Forum holiday Inn

An interesting day at this seminar organized by The Brain Tumour Charity. There really is a lot going on giving real reason for hope. As usual there is a patient experience session. I see this patient was diagnosed in 2004, a year before me. Further evidence of reason for hope. However, when he speaks, it's a story of going from one operation to another. I'm embarrassed when one of the organisers picks up on a point saying "I think we have David Grant with us today. You encountered the same thing?" I find myself on my feet talking lucidly, but I just want to sit down, this is not my show. well done mate. Dave, you have been lucky, one operation, a course of treatment and you are living life to the full, free of cancer medication.

19.03.2013 - House of Commons and meeting with a Health Minister

To the House of Commons and a meeting hosted by Headway, a children's cancer support charity. The Health Minister, Anna Soubry is the speaker. One of the areas she wants to hammer is the notion, admittedly not heard so often now, that Brain Tumours are not a cancer. I was able to have a discussion with her on the Equality Act. Macmillan is charged with doing a report on how well employers have embedded the act into their processes and culture. She was appalled on hearing a recent story.

02.04.2013 - Return to Worldpay

With a clean report from the WorldPay appointed Occupational Therapist, I thought I'd quickly be called back to work, but it was to take a further month for a chain of "decision" makers to make up their minds that the sensible and decent thing was to invite me back. I returned today, my birthday. I was furious. I felt my reputation had been diminished. You do not treat people like this and doing so to your top performer was simply inept.

16.05.2013 - MRI scan at St Thomas'

To St Thomas' for the usual MRI scan, my 22nd since the op. Goes off smoothly with the injection to enhance the image done on the scanner. Now await the results.

23.05.2013 - Dr Beaney and the scan results

I had no reason to believe the results would be anything but good, but I'm taken aback when he tells me that I am simply "Thriving" not just hanging on. Thinking back on our meetings, I remember our first meeting concluding with him telling me that some patients do very well, "join them!" Later he described as being in a "small group", then a "very small group", etc. I started to think of the faces I saw back in 2005/6. I no longer saw those faces. I have been fortunate.

Thinking about it, he would have had feedback from medics on a presentation I'd done to doctors at a Kings premises near the IMAX cinema. His nurse Vicky had arranged it. I'd spoken for 35 minutes without notes, and could see they were impressed. It was probably feedback on that presentation that elevated a clean scan to "Thriving" status.

05.07.2013 - last day at Worldpay

I remained furious with the way I had been treated and we came to an acceptable financial arrangement for me to leave.

In what turned out to be a 2 day festival of celebration of DG I left with so many good wishes. It was with more than a degree of sadness. The team were as appalled as I was at my treatment. I left with a good settlement, leaving a greater understanding of the Equality Act 2010 and no excuses for a repetition with anyone else.

17.10.2013 - 11+ plus success

An announcement from Claremont Primary School. Our daughter Lauren has passed her 11+ exam. She will now follow in the footsteps of mummy by going to "TWIG's". Back in 2005 I pledged to walk her to her first day at school. A new target now ` I will

be here to welcome her home from her first day back from senior school. I will be so proud.

05.11.2013 - MRI scan at St Thomas'

To St Thomas' for what is my 23rd post op MRI scan. A couple of the radiographers recognise me from earlier visits. One says "you have a daughter, you are looking so well. After a chat, I leave quite lifted.

After an excellent lunch in the Tom's canteen (I just had to fill up the customer feedback form with some praise) its off home to await Thursdays feedback from Dr Beaney.

07.11.2013 - Dr Beaney, scan results and a splendid day

The day starts with me finding a synopsis of my journey published on an NHS website (NHS managers.net). They've attached a link to the pdf of "Survive and Thrive v2.0", giving me a chance to get my message across in the NHS. I like the preamble they've given me "Listen to a man who knows...."!

Before travelling to London, I pop into Town with Lisa and we try out a new cafe. As usual get to the station in plenty of time. There is a problem, with 40 minute delays but here comes a train. It might be 40 minutes late to you but it's 20 minutes early for me! With plenty of time I ring David in my old office, and meet up for lunch with a large glass of wine (red). Then off to St Thomas's to see Dr Beaney and get the results of what is my 23rd post op MRI scan. If you sit and ponder you can always think of some reason why this scan could be a bad one but in truth you cannot tell. These are highly sophisticated machines, designed to spot a problem before it is evident to you. I need not have dwelled "that scan was absolutely perfect" he skips the usual psychometric tests as there is nothing wrong. excellent! We discuss the work I'm doing with Macmillan and next week's presentation at St Georges. He's pleased I'm staying active and I tell him of my intention to get back to some paid activity. I offer him my thanks and leave to call a delighted Lisa and a few friends.

On the way home I pick up a box of Celebrations chocolates. With such good news, Lauren will expect some evidence. Chocolates, yes that's the sort of proof she'd expect.

Turning in at the end of the day I do a last minute check on my email. Just one, its from a Doctor. He's read this morning's bulletin and is asking if I would contribute to a book he is writing on how patients can get the most out of the NHS. I would be delighted to help. I turn off the lights. a splendid day.

15.11.2013 - St George's, UCL - lecture on patient messages

Whilst I was here in January, my lecture has been brought forward a term and here is another crop of students. Now the fourth year I've given the "expert patient" talk to medical students studying for an Msc in Rehabilitation. I take them through my journey bringing out instances of poor communication! I always enjoy it as I get instant feedback that things could be done better and they as individuals will act appropriately. This year I have 16 students. I always put a lot of effort into practice: gargle, practice,

gargle. The story is well embedded in my mind, but it's about getting a message across. I wanted to push a "think patient" line and feel my message got across. I was on my feet for more than 50 minutes and was pleased with my performance with voice and delivery holding out without any wavering.

I would be very pleased to be invited back a fifth time.

12.11.2013 - by way of confirmation

A copy of a letter my consultant has sent my GP arrives. Headed "Right parietal Glioblastoma multiforme" it reads "It is almost nine years since this patient had his high grade brain tumour diagnosed and treated with surgery, radiotherapy and chemotherapy. When seen today, he is remarkably well with no symptoms, signs or indeed radiological evidence to suggest a recurrence".

Thank you Dr Beaney. Thank you.

Summary

With the cause of Brain Tumours still unknown they'll never say I'm cured. If the cause of brain Tumours is not known, how do they know they've fixed it? However, "absolutely perfect" and "thriving" are good enough for me. Consider that not everything went to plan with diagnosis just days after a past sell by date yoghurt was cleared and a platelets crash preventing the final week of Temozolomide in phase 1. Now more than 8 years on, against all stats I'm here living life to the full. My last cancer medication was in July 2006. Since 2005 things have got better with Temozolomide now on the NHS, back in 2005 even the manufacturer was only claiming a 3.1 month average improvement; more improvements in side effect drugs and more and more clinical trials. Those stats are only going one way, so believe in yourself and join me.

In closing, I still cannot think of any more suitable words than those I used to close Editions 1 and 2. Thank you to everyone, this story is to be continued.

A free download of this publication can be obtained from www.lulu.com

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Useful websites

I've found the following charities to be of great support and worth contacting:

BT Buddies. Registered charity No. 1153487 www.btbuddies.org.uk

Brain Tumour Research. Registered charity No.1153487
www.braintumourresearch.org.uk

Hammer out brain Tumours. Registered charity No. 1102750 www.hammerout.co.uk

Macmillan Cancer Support. Registered charity No: 261017 www.macmillan.org.uk

The Brain Tumour Charity. Registered charity No. 1150054
www.thebraintumourcharity.org

For information on what is happening elsewhere, a look at the site of the U.S. National Institutes of Health (NIH) may be of interest: www.nih.gov.

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