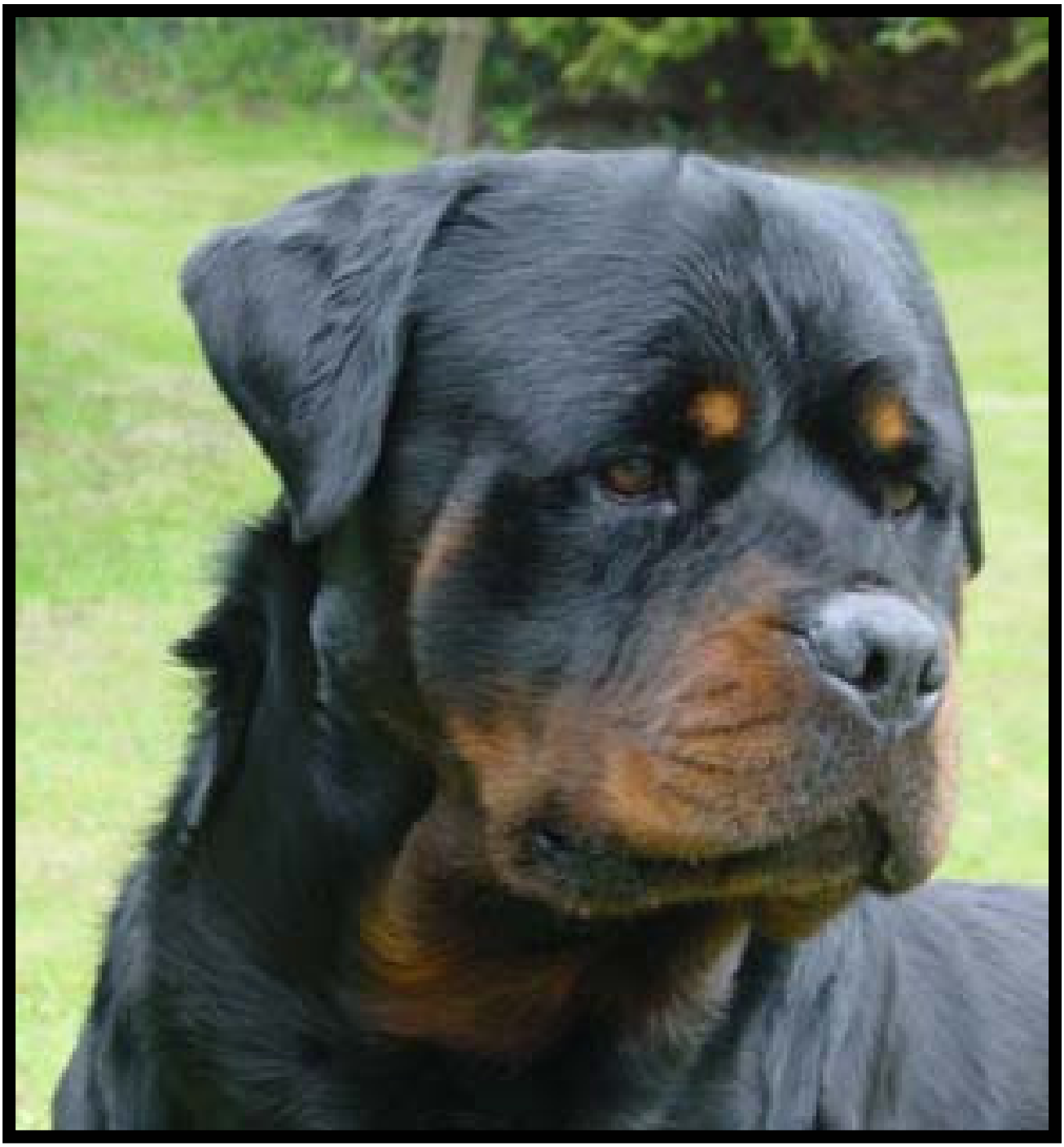

"What exactly is your point?" [The Rottweiler responds to criticism of his contribution]

"A Rottweiler, Frank & I"

Part One – Some Recollected Matters

Edition 4.1 October 08

[First Published June 2006]

1

MEDICAL MATTERS

LIKE A RUNAWAY TRAIN

So there you are, not so much riding the rollercoaster of life, more driving down its motorway on cruise control, when:

1. You are made redundant without any warning after 10 years with your current employer.

2. During a routine shopping trip, you wake up in the local A&E ward without any knowledge of how you actually got there - I know what you're thinking but please don't judge us all by your own standards.

The staff – who bore very little resemblance to those dedicated ones working in shiny hospitals on BBC1 - give you the news; they have "*found something in the scan*" and you are to be referred. In this case, referral meant an immediate ambulance ride in the depths of night to another hospital.

To reduce the dramatic tension somewhat, have you ever been lost in an ambulance on a hospital approach road network? "*It must be straight on here, no… erm…didn't we take that turn the last time? Ask that chap over there…*"

Referral is, as we will later see, a very significant word defined in the dictionary as "*... to have recourse to some authority; send on or direct...*" The recipient hospital – particularly charmless and built as a form of concrete shrine to the 1960's – conducts some further tests.

The Consultant and Oncology Nurse now invite you into whatever spare room [or broom cupboard] they can find to pronounce the verdict - you have a Brain Tumour that, due to its location, is very likely to be terminal.

Immediate surgery is recommended and the risks of various options are mentioned. This process is called "*Informed Choice*" and, like referral, it will be a theme that we will return to later. At what point do I actually wake up and find that this rollercoaster ride is a dream? Actually, a rollercoaster ride has an up and a down – I was only receiving "*no news or bad news*" at this time.

By coincidence, a BBC1 programme *Life on Mars* about a policeman who, after a car accident, awoke back in 1973 provided an eerie backdrop to the unreality of the events unfolding before me. You should note however that my Consultant did not wear flares and instead [rather worryingly] resembled Uncle Albert from *Only Fools and Horses*.

The required procedure – a Craniotomy - will also include the taking of a sample for biopsy to confirm the classification of the tumour. What is a Craniotomy? Try thinking of how you eat a boiled egg if it helps. Apparently, there is an official scale used in these matters running from "*Fluffy Rabbit*" to "*Furious Rottweiler*". Actually, this is not true, the use of adjectives was recently banned in the NHS following new government guidelines – they are now considered as being too discriminatory. In their place, a rather more prosaic Grade I – IV scale exists.

Erin Dawes [pictured middle] discusses the impending operation with the Consultant and Hospital Registrar

HEROISM IN THE FACE OF BOREDOM

For somebody who had rarely had cause to even consult a G.P, an extended stay in hospital was a new experience. Not having any obvious symptoms meant day after day of waiting with nothing to do – especially as the NHS patient day is very long with routine tests performed at 0700 and 2230 and the time in between being punctuated only by noise. Whilst waiting, I could not actually leave the hospital as I would then lose my place and the operation would not be performed as planned.

A patient in the next bed had obviously suffered a head injury and was not yet "*compos mentis*". The meals were delivered to him and then collected some time later – "*Not hungry today then?*" Many – but not all nurses – were clearly graduates of the *Rosa Kleb School of Nursing*. I can only imagine that this was how it felt to be a prisoner of war – I of course had the stoic Alec Guinness type role. "*…despite this overbearingly intense heat, we must stand together against the enemy chaps…*" [Steady on now, don't overdo the metaphor.]

Eventually, after the operation and nearly a week of post operative monitoring, I was released back into society and there followed an anxious wait for the definitive biopsy result. This was eventually communicated to me at home [by telephone] as being; "*No trace of tumour found.*"

This mantra was then repeated endlessly in the face of my obvious questions. The result had of course identified the need for another broom cupboard liaison. What does it all mean – am I now OK?

Which of the following do you believe to have applied?

A. A bearded, very irritating man came out from behind the curtain and revealed that it was all a jolly TV prank.

B. I was advised that "*it is illegal to discriminate against tumours and therefore the matter was being taken very seriously [Sir]*"

C. It was later revealed as a gross act of negligence on behalf of the hospital and I appeared on GMTV [being interviewed by the "*twittering*" one] as well as receiving handsome compensation.

D. It was simply a fact that the bits they originally took out could not be identified in the *Haynes Manual for Brain Surgery* and further samples would be required to classify it. A Stereo-tactic biopsy will now beckon; what is this? Have you ever seen an Eskimo fish?

If you would like to take part in this competition, please send your answer [with money of course] to:

THE ANSWER IS "D"
ANOTHER PHONEY MONEY RAISING NON-COMPETITION
CAROL VORDERMAN'S TV WORLD
GMTV
P.O BOX 1234

Why not text your answer? Send any long word to 12345. Standard rates of £1 / entry plus £1 per letter will apply. Don't forget to get the approval of an adult – anyone will suffice [even that strange one at the bus stop.] Winners will be announced – honestly!

THE WORLD IS YOUR LOBSTER [courtesy of Arthur Daley]

So, there you are, this chain of events explains how I became the proud owner of a Rottweiler [sorry Grade IV tumour]. Actually, I would hate you to assume that I have been using alternative therapies such as *Visualisation*. The Rottweiler – without any name – didn't actually exist in case you are still confused. The tumour called *Glioblastoma Multiforme* unfortunately did.

The final broom cupboard meeting waves you off with the standard prognosis - one year or maybe two years life expectancy. As a private patient, I also received an additional [but chargeable?] pearl of wisdom; "*You will never be better than you are now, so get out there and enjoy the time you have left!*" This is somewhat akin to being driven to a cliff edge and then being asked politely "*What would you like to do next Sir?*"

Unfortunately, there also remain a couple of academic points to mention:

1. You will find obtaining suitable travel insurance at an affordable price [if at all] extremely difficult.
2. Ah yes, and there is also the little matter of further treatment.

A FULL RECOVERY IS EXPECTED

Before my recent experiences, I would have assumed that this very significant medical phrase meant that everything would revert to normal after some brief medical intervention or crisis.

I now realise that it only relates to the conclusion of an individual procedure. It is therefore perfectly possible to have a "*full recovery*" from an operation without actually curing your particular ailment.

I cannot understand why this ambiguous phrase is used - unless to deliberately avoid revealing the more complex reality of the situation to a patient. Sadly, I can report meeting at least one that could not appreciate the subtle difference based on what they had been told.

Whilst I have the dictionary out, it is also worth mentioning "*Remission; [noun] diminution [reduction] of force*". There is a public misconception when headlines claim that somebody is "*in remission*" that the turning point has been made and the path to a complete recovery inevitably beckons.

Sometimes, but not always, the situation may indeed allow for such a favourable interpretation of these phrases.

RAIN IN THE MORNING, RAIN IN THE EVENING

Success in the handling of terminal Brain Tumours is always going to be relative and therefore very hard to define. The resolutely gloomy prognosis offered to me so far led to my undertaking further independent research – something that I recommend anybody in a similar situation doing.

A few immediate conclusions I drew were:

1. Early diagnosis [and therefore commencement of treatment] is critical to success. I was fortunate enough to present symptoms that required an immediate scan. Incidentally, I love that medical phrase "*the patient presented symptoms*"; would Sir like them gift wrapped for that special touch? Others might have months of tests [and even misdiagnosis] before reaching the same point – possibly too late.

2. Your age and general health are predetermining factors. I was "*lucky enough*" to be diagnosed in my early forties – a double edged sword if ever I saw one though!

3. Successful cases often involve patients who concurrently adopt a vitamin and herbal supplement regime - thus forming a more integrated approach to treatment. This is of course a subject in itself and, as this book is not intended to be a reference guide, I do not propose to take the matter any further. Incidentally, finding anybody to give a balanced view – or even to consider it a serious option – from within the NHS is nearly impossible.

4. Be wary of US web-sites where the claims of success in attempting various alternative therapies are the more fantastic with supporting evidence such as "*she was given a month to live*

three years ago so imagine my surprise when she passed me in the New York marathon!" Disregarding the plainly bogus claims, I think I can explain this phenomenon from first hand experience. Once people are aware of your situation, your disappearance for a time from normal contact leads them to an unconscious assumption that you are already dead. Any subsequent sightings will therefore create potential astonishment and it is this that fuels the mythical claims.

You should now use your accumulated knowledge to make decisions on what you personally are going to do. I resolved not to return to the huge volume of material – of varying quality – available on the internet. As far as I could see, there appeared little point in buying time just to use it reading about the condition or treatments.

A FORENSIC EXAMINATION

For such a rare condition you might be surprised by the total lack of interest expressed in my personal and medical history – not exactly Quincy ME then. I happen to know of three cases [when including my own] all from an area of less than a hundred or so square metres.

In addition, when I visited my G.P after discharge from hospital, I noted that he did not appear to be *"firing on all cylinders."* A few weeks later, a note appeared in the surgery window giving the sad news that he had been diagnosed with the same condition.

Whilst these are probably just an unhappy coincidence, for those seeking answers, reading the literature on the subject will enable you to comfortably rule out all possible contributory causes – what a relief then!

Incidentally, talking of Quincy earlier; in the 70's crusading, dedicated and fearless [to a fourteen year old viewer] soon becomes pompous and self righteous today; a nightmare employee – how flexible would he be with his holiday entitlement for instance?

PLAN B? – THERE ISN'T ONE

Back in the NHS, a post-operative treatment plan would now be developed using a balance of radiotherapy and chemotherapy. These are the only options offered and surely fail to grasp the possibility of a complex multi-disciplined approach to these matters.

As my general health and age were on my side, it was proposed to try *Radical Radio* – incidentally, this has nothing to do with pirate stations playing cutting edge urban beats. *Radical Radiotherapy* actually

involves 30 doses over a six week period adding up to your life time safe exposure limit to radiation.

Chemotherapy can start concurrently, or immediately afterwards, and the drugs used will still depend on whether you have private medical insurance – Brain Tumours are not as common, or as well publicised, as breast cancer. Having insurance gave me a wider range of options but, earlier on, I had to fight to get this recognised as my consultant felt that it should not play any part in the treatment option availability. True though this might be from a moral perspective, it would have been positively perverse of me not to pursue this path having paid the premiums for many years.

Standard protocol now determines that this process continue indefinitely [only being punctuated by monthly consultations] until your health dictates otherwise.
Your further options would then be based on:

1. Repeat surgery – carrying obvious risks with an uncertain return.

2. Minor changes to the existing chemotherapy regime pending any alternate drug developments.

People often refer to chemotherapy as "*chemo*" – as if, simply by giving it a small friendly name, it somehow makes it easier to deal with. Fancy a spot of chemo tonight? No? What about a curry then?

Chemotherapy damages the bone marrow thus affecting your white blood cell counts. Protecting your immune system is therefore very important and makes the lack of a multi-disciplined approach – as mentioned earlier – all the more disappointing.

If your levels do fall unacceptably, antibiotics may be suggested as an additional option to reduce the risk of rare [and possibly fatal] infections that the body can normally just shrug off. As I have always been wary of taking drugs just to counteract the side effects of others – it seemed to me that this was a slippery slope – I attempted to achieve a satisfactory result [when facing this very situation] with my own herb and vitamin routine. As the readings returned to normal, I did feel somewhat vindicated but, as always, I would urge you to weigh up the evidence and make up your own mind. Unfortunately, it would be impossible to have examined the potential outcomes of the two alternative paths so it remains a matter of faith.

SIX MILLION DOLLAR MAN

I used to regard private medical insurance as being expensive. Having now had a range of operations and treatments, I have collected a rapidly rising series of bills. As an example, a routine monthly round of chemotherapy [with its associated consultation] costs my insurer £1500.

It is obvious that it is wrong for people to be denied appropriate treatment but, ultimately, somebody somewhere has to actually pay for it. It is also not a problem that can simply be laid at the door of the pharmaceutical companies, as development costs and approval timescales for their investments are significant.

Legislation would only serve as a disincentive to research and development into new treatments. The typical TV portrayal of a patient denied treatment therefore adopts a simplistic view that very few viewers would argue with; the overall balanced picture is usually ignored.

It is likely that your own opinion will ultimately be informed only by your personal circumstances, an uncomfortable thought? It should be.

Principal of "Informed Choice" – A simple guide

[The game continues until the options are reduced and/or your time runs out]