

THE PROSTATE

SMALL GLAND **BIG** PROBLEM

By John Crow

Chapter 8

MY STORY

For many years I had been giving donations to a variety of charities including Cancer Research. One day I had yet another unsolicited mail from a charity unknown to me, '**The Prostate Research Campaign**'. This mailing very nearly ended up in the bin but for some reason I felt compelled to read it. This proved to be a wise move indeed and along with other prophetic happenings has been partly responsible for saving my life.

The charity needed more funds into research for this 'men's problem' and had for sale a book written by a leading urologist, Professor Roger Kirby, with the proceeds of the book helping fund further research. Having read it, it dawned on me that I had some of the symptoms mentioned so I started to monitor myself, but other things in life took over and I ignored them and went off to Singapore for a holiday. However during this holiday I noticed that my symptoms were becoming worse and upon my return home I found that I was having to pee a lot and get up during the night perhaps four or five times. Eventually I went to the doctor who immediately diagnosed prostatitis and duly doled out the obligatory prescription for antibiotics.

To cut the tale short, after three visits and three different antibiotics I insisted upon a consultation with a urologist, but as there was the inevitable waiting list I elected to pay for this privately, another very wise move it would transpire.

The **DRE** and subsequent **PSA** tests were performed. My **PSA** came back initially at 27ng/ml which under normal circumstances would have meant nothing to me or indeed any other man, unless of course he had read the book by Roger Kirby. This is the point where the second prophetic happening, my support of Cancer Research, comes in. I have to say my comments to my specialist in the wake of the PSA results rather shook him because I knew in my heart (or water if you'll pardon the pun) that I had cancer. But unbelievably, and despite the very high PSA, the specialist gave me two options. Watchful waiting or have a biopsy performed. Needless to say I elected to have the biopsy, not the most pleasant of experiences, and I can confirm that it makes one's eyes water.

In **March 2002** when I went back to see my specialist he told me that I had a moderately aggressive cancer with a **Gleason Score** of 6. Having already done my own research I had gained sufficient knowledge to realise that it was highly likely I had prostate cancer, so when this was confirmed it was not such a shock as it otherwise might have been. My opinion is that the cancer had been lurking around for perhaps up to two years prior to this.

What happened next? Well, I took control of the situation and decided that this little bugger would not in any way beat me, but faced the fact that I would require treatment to help me along. Various MRI and bone scans followed to see how far the cancer had spread. As my PSA had now risen to 32ng/ml my options were limited and a **prostatectomy** was ruled out for fear of exacerbating the situation by making an incision. I elected to have hormone therapy (to reduce the tumour size) followed by nearly seven weeks of radiotherapy. I have to say that at that time I became rather forceful (growling like a Tiger!) and insisted in starting the treatment immediately.

In total I have had over 270 hospital appointments over the past nine years but must say I am in good shape, so much so that I recently embarked upon voyages to both Antarctica and the North Pole.

Who knows what is in store for any of us? The moral of the story most definitely is get on with life, enjoy and respect every day. Live your dreams now, not when it is too late or you are not able.

When I asked my oncologist 'how long do I have left?' his response was 'between five minutes and fifteen years dependent upon whether you are run over by a bus when you leave here'. This did appeal to my sense of humour!

Not wanting to accept that I would be taking hormones for the rest of my life I decided to explore other options.

Since originally writing this article things have taken a turn for the worse and my PSA has started to rise at an alarming rate. In an effort to try and stabilise my condition I have been taking part in a clinical trial. However I have not responded as I would have liked.

Then I read about a relatively new technique called **HIFU** (see Chapter 5) as a result of which I met Mr Mark Emberton at the University College Hospital London where the procedure was duly performed in **June 2006**. And all was well until **December 2006** when the PSA started to rise once more. So what now?

Following an MRI scan it has been established that the apex of the prostate gland may not have been treated fully during the HIFU procedure, so I have now undergone yet another procedure, namely a **3D Mapping Biopsy**. This should pinpoint any remaining cancer which may then be retreated with either repeat HIFU or cryosurgery.

We move on to **October 2007**. I have just heard that two areas of cancer have been found during the **3D Mapping Biopsy** so I am optimistic that I have yet another chance of further treatment.

December 2008. My third salvage HIFU has bought about a fistula between my urinary tract and rectum which basically means I am passing urine through my rectum and faeces is passing in reverse. E-coli is ever present in this situation. Whilst HIFU obviously has a place as a treatment option, any person contemplating this procedure must be aware of the potentially catastrophic results requiring in my case at least four major operations over the next two years. This includes prostate and sphincter removal, the fitting of an artificial sphincter and not forgetting the many indwelling suprapubic and urethral catheters.

This has literally destroyed my life, so be warned you guys. Ask many questions before you take this route..

June 2010. Since my last report, much has taken place. As a result of the catastrophic fistula mentioned above many difficulties arose including e-coli infections and faeces passing through from the rectum into the urinary tract, eventually being expelled unpleasantly through the penis. At one point the urethral catheter was forced out under pressure and exploded on to the bathroom floor. Many hospital admissions followed for various reason too numerous to detail in this report. Following many scans and discussions it was agreed to proceed with the somewhat radical and specialised surgery which, I had been warned, would not be without its difficulties, both during the operation and post operatively.

The entire process has caused unimaginable pain and suffering and there have been many moments of despair when I wondered whether I could endure anymore - or even wanted to for that matter. But the survival instinct is extremely powerful with always a glimmer of hope, so life goes on. But sadly there is not a great deal of good news. The fistula was eventually sealed after some extreme cutting edge surgery performed by Professor Mundy at the UCLH. The operation took some eight hours and involved making an abdominal incision from just below the breastbone down to the lower pubic area. A further incision was made to open up the perineum, thus gaining total access for the procedure to be performed.

The procedure itself required taking tissue from the stomach area and interposing it into the rectal area of the opened fistula. At the same time, a salvage prostatectomy was performed as this organ had been so badly damaged by radiation and HIFU treatments as to render it useless. With a large hole in it, it had formed the other end of the offending fistula. At this point the now open urethra was joined from the bladder neck to the distal urethra. I awoke some eleven hours later to find I had more attached tubes than the London Underground and in pain and distress. Gradually the various tubes were removed over the following week but the two catheters, one suprapubic (through the abdominal wall) and the other passing through poor 'willy'. At least I was placed in a side ward offering some respite from the usual noise and actively associated with a hospital stay.

One of the immediate side effects of this surgery was that I developed an AF (Atrial Fibrillation) of the heart which was of some concern requiring further exploration. Many tests and procedures were performed and I was advised that my heart is actually very healthy but the electrical signals from the brain seem to have become mixed up thus making the heart beat irregularly and sometimes extremely fast at over 200 beats per minute. Some two weeks later I was allowed home, gradually recovering though now rendered totally incontinent which was, and still is, so unpleasant and restrictive.

An abdominal abscess formed on part of the wound where it was found that two pieces of deep muscle suture some 7cm long had been left inside and had been rejected by nature. These were removed and the wound healed. To add to my difficulties and as a result of this major incision I have now developed a large protrusion in my abdominal wall. This is most likely a hernia and will require further intervention to put right. Unfortunately the horror story does not end there and the saga goes on. It was hoped that the major surgery would have served two purposes, one being to seal the fistula and the other to rid me of the remaining cancer but this is not the case and my PSA continues to rise.

At this point I had a further major set back which almost killed me. I had felt a little unwell for two days but was suddenly very ill indeed with a high temperature and violent shivering. Although the on-call doctor said it was nothing to worry about and to stay in bed with Paracetamol, I became increasingly unwell and was physically sick. At this point I thought I was about to leave this planet and asked my lovely wife to call for an ambulance. This arrived with little delay and took me to A&E where I was transferred to ICU with severe septicaemia, so more tubes and monitor invaded my poor body and I remained in ICU for six days being pumped full of no fewer than seven antibiotics in an attempt to bring things under control. Scans and x-rays were also ordered. I spent a further two weeks on the ward before being sent home but a few days later I felt unwell again and my AF could not be controlled even with medication. We called the ambulance once more. Further investigation followed along with yet more scans and x-rays and it was found I had developed a pocket of fluid around my heart and in my left lung. I spent another two weeks on the ward, all wired up to monitors and drips. I keep wondering how much more I can take.

Following a post operative exploratory procedure a further secondary prostatic tumour was found in my bladder but despite this being removed the PSA continues to rise, indicating possible metastatic disease. Every type of scan possible was performed at this stage in an attempt to locate the cancer. The scans for those interested were BONE, MRI, CT and PET. Much to everyone's surprise they were clear except for areas indicative of arthritis in the lower back and right hip.

Now we have a dilemma. The PSA continues to rise thus indicating microscopic disease somewhere in my body but too small to be picked up on the scans. It had been planned to fit an AUS (Artificial Urinary Sphincter) at about this time. However a stricture has developed in the bladder neck area necessitating yet more invasive surgery to remove the stricture and reconnect the remaining good tissue (if there is any left): but with a rising PSA this is considered too dangerous. As a result I am now taking anti-androgens (hormones) in an attempt to bring the PSA levels down. If I am lucky, and believe me I do need some luck now (please) and the PSA

decreases, we may be in a position to proceed with the necessary surgical procedures to help me spend my remaining years with some freedom and quality of life.

I hope my next report will bring good news but in the meantime I will yet again reiterate my parting statement in my update of December 2008. **Do not allow relatively unknown treatments to be performed without triple checking all the risks.** My life has been radically changed and will never be the same again with many normal activities been curtailed in one way or another. I have suffered the most unimaginable pain and trauma, not to mention the 297 hospital visits since first diagnosis, 58 of which have involved a train journey to London. Until next time with hope and perhaps a light at the end of the tunnel.

November 2010. I really wish I had some good news but sadly not.

Since my last update; following an exploratory at UCLH, I developed Septicaemia and a further quite frightening heart problem again, both of which kept me in hospital for a further nine days.

A subsequent meeting with the professor has brought the news that no further interventional procedures would be wise until the heart has been brought under control. In fact the Prof was honest enough to say he didn't want to be the one to kill me. Food for thought or what!

So, there we are, but despite all this, I still remain quite well apart from the inconvenience and irritation of a rather large tube (Suprapubic catheter) through my abdomen and into the bladder. The hormones are doing their job as are the two heart drugs .My PSA is down to 0.5ng/ml and the heart has settled to a steady beat. The challenge is to see what would happen without this chemical attack on my body. I will have a review meeting in London in January; in the meantime life must go on .Until next time...**Tiger Tiger**

The current position: February 2011

Since my last report, following yet a further hospitalisation due to Septicaemia, I have seen the Professor in London, who has advised that I now cease further treatment, as so much damage has been done that it is doubtful the proposed AUS device would be successful. I now have to live with a size 20CH Suprapubic catheter for the rest of my life. This is a very tough call indeed but a challenge I have to face. On top of this catastrophic mess, my cancer is still lurking somewhere so I must remain on the Hormone treatment to try and hold it at bay.

To further add to my nightmare, the professor found a huge abdominal hernia some 5 inches long, which will require quite major surgery at a future date. How much more I can take is up for debate.

Who said life was easy?... **Tiger Tiger**