

'YOU'RE ONLY AS GOOD AS YOUR LAST PSA'

A PROSTATE CANCER CASE STUDY

Tuesday 9 December 2014

I got some good news this morning: my PSA was 0.01, all but undetectable, for the fourth quarter running. That doesn't mean the war is over – it never will be – but it gives me enough of a new lease of life to motivate me to take up my pen. PSA by the way stands for Prostate Specific Antigen. The PSA test is a blood test that measures the state of your prostate cancer. But it is fallible. More on that later.

July 2008

'Good morning. Do sit down'

We sit.

'Your name is (my full name)?' 'Yes'

'And you live at (our address)?' 'Yes'

Whatever was coming next?

'Well, I'm afraid I have some very bad news for you.'

We were in a small but crowded room at Bradford Royal Infirmary (BRI). It was the weekly oncology (cancer) out-patients clinic and the consultant was giving us the result of the biopsy I had had a few weeks before. He went on in similar vein: 'Some of them are pussy cats. You have a tiger.' I discovered later that these are actually technical terms, used to distinguish between more and less aggressive cancers. At the time I felt a momentary thrill of pride: I had a tiger in my tank! Dread swiftly followed as he spelt out the detail. I had an aggressive cancer of the prostate with a 'Gleason' score of 7, the maximum being 9. It had not yet spread further but was close to doing so. Surgery was the answer and he was a surgeon. He felled me then offered a hand up.

There was an alternative remedy, radiotherapy, offered at Leeds, but he was confident that the Leeds people would agree that in my case surgery was the

obvious choice. We saw the Leeds people next. They did not agree. Naturally they made the case for their kind of treatment but I was in such a state of shock that I probably did not give them a fair hearing. The major drawback with radiotherapy, it seemed to us, was that surgery was not possible later if it failed, as surgeons could not operate on irradiated flesh, so if two bites of the cherry were needed, surgery had to come first.

I was overwhelmed by the urge to get rid of the thing. I felt like I was harbouring an alien. The sudden dawning of mortality, possibly imminent mortality, was a huge shock to one who had always had the good fortune of good health. I was 64 (the song assumed new meaning now) and I suppose I was banking on at least another twenty years. I had three lads, two of them quite young. What would my loss mean for them? It was not a good day at the office.

What I should have done – ah, what I should have done - was grasp at the straw that prostate cancer is relatively slow-growing. I should have taken the time to explore other options, especially what is called ‘watchful waiting’, and also to allow the probable after-effects of surgery to sink in. The after-effects are urinary incontinence and impotence. In my shell-shocked state I could almost have accepted the loss of a limb as a price worth paying. Incontinence and impotence have clear meanings but they are hard to imagine until you actually experience them, and after surgery unfortunately there is no cooling-off period. You can’t send the goods back.

The urge to get the thing out, however, was so strong that I went ahead at full speed. Within six weeks the deed, a radical prostatectomy, was done. The surgeon did not of course guarantee a full cure but he thought he could give me 5-10 years, and in order to maximise my chances he decided to remove as much as he could – what is called euphemistically ‘non-nerve-sparing’ surgery. This makes a recovery of potency all but impossible.

A Step Back

I had first come across prostate cancer years before when I picked up a leaflet at the GP’s surgery. I did not keep it and could never find it again but what it said about men of a certain age taking the PSA test stuck. So one day in my 64th year I went to see my GP to ask for one. To my surprise she was clearly reluctant. She

had two main arguments: firstly, the test is unreliable. It gives false positives and false negatives. In other words, it can be falsely reassuring or falsely alarming. Secondly, many older men have some sort of prostate problem, not necessarily malign. Because the cancer is slow-growing most men who die with it do not die of it. It is found at the autopsies of most men over 80. I asked whether she was in effect saying that ignorance is bliss. Yes, she said. But she gave me a three-page article to take away and said that if after reading it, I still wanted the test, she would arrange it.

What I felt weakened my case was the lack of symptoms. This is another known feature of this particular cancer and it obviously makes it harder to ask for a test; however, this is a very common cancer, with over ten thousand men a year in this country dieing of it, and in my experience ignorance is rarely bliss. So ten months later I went back to the practice and saw another of the doctors. Sure, he said, you want the test, you have the test. It came back with a PSA score of nine, just high enough to trigger the next step, a biopsy. This too is controversial. The result of the biopsy, where actual samples of the prostate gland are obtained through a procedure not best known for its dignity, was the reason I was sat before the consultant that morning at the hospital.

Repent At Leisure (1)

After the operation I was monitored at six weeks, then three months, then six months. Monitoring was through the PSA test, which perversely becomes a more reliable indicator when the gland itself has gone. At six weeks the PSA had come down from nine to 0.08 - 'undetectable'. At three months it was the same. But at six months, nearly a year since diagnosis, it had gone up to 0.12, a rise the consultant described memorably as, 'small but probably significant'. The relapse was under way. For all the non-nerve-sparing nature of the surgery, it had not been a totally clean sweep. Something had escaped and was on the go again.

For the consultant and his team this meant a recommendation to proceed to the fall-back option: radiotherapy. For me, since the surgical 'big bang' solution had failed, it meant a complete re-think. I had put my faith in the men in white coats but they had delivered the costs of treatment without the benefit. Maybe it was time I started to take a hand myself. In the year since the operation I had not exactly buried my head in the sand but nor had I taken much interest in finding

out about my condition. Maybe I didn't want to know. What little research I had done just depressed me and it was depressing enough learning to cope with my new-found incontinence and impotence.

Now I came to understand the consultant's care in distinguishing between what he could *do* and what he could *promise*. What he could do, and had done, had been presented as the best option but it came with no guarantee. I was resentful at the damage done to me for, it was now clear, no gain, and it was easy at that moment to forget that the real enemy was the disease, not the people who spend their lives fighting it. My GP once described cancer to me as 'crafty'. Fighting it calls for all hands so what, I suddenly wondered belatedly, was I doing sitting on mine? I have spent most of my life working and campaigning for causes that had little to do with me personally. This campaign was going to be very personal.

Throughout these twelve months I had been blessed with the company, advice and practical help of my partner. I don't know how I would have fared without her. We looked online. The first book we found was Jane Plant's, 'Understand, Prevent and Overcome Prostate Cancer'. That seemed to fit the bill. It came and the reading started. It was indeed a good book to start with. I shall always remember the most vivid chapter heading: 'Milk is a four-letter word'. Over the next few years I read little else but books on cancer. Sad but necessary. They were on the whole readable, knowledgeable and persuasive, although for a non-scientist it was not always easy to judge their authenticity. There was naturally a wide variation in detail but a convergence on the core issues. One consensus that emerged was for a plant-based diet. Going dairy-free turned out to be just the start.

Meanwhile the PSA continued to rise slowly (now 0.15) and a month's radiotherapy was scheduled for November 2009. On weekdays for four weeks we went to Leeds where I was zapped from four angles. The target was the prostate bed although without an actual prostate gland to aim at, this seemed to me a bit hit and miss; after the thorough scraping by the surgeon, who could say where the malignant morsel might be?

I had already started to give up all dairy products and I arranged an extra PSA test just before the radiotherapy to see if a month's dairy-freedom had made any difference. At first it seemed as if it might: the PSA was 0.14. We clutched at this

straw, but 0.01 is well within the margin of error and besides we had hardly begun to realise how widespread dairy was in our food, and naively believed paying off the milkman was all there was to it. We slowly learnt a new kind of shopping, where you put your reading glasses on to scrutinize the label of every tin and packet.

Digression

On the 20th and last day of the radiotherapy a strange thing happened. I had been warned to expect fatigue and even burn marks but neither happened. Instead on this last Friday I had a new and not very pleasant feeling. It got worse over the weekend and other symptoms developed: blurred vision, unsteadiness, constant hiccups. I went to the GP who ordered a blood test and later that evening, as I lay half asleep and feeling sorry for myself, I got a call from the Out of Hours Service to say I should go to A&E immediately. A&E – OMG! – couldn't it wait till morning? If I were you, came the firm reply, I would go now.

We went. After the customary four hours I was admitted. All I remember of the next 24 hours was the drip attached to my arm which seemed to be more of a waterfall than a drip. After a few days came the diagnosis: Addison's Disease. This is a failure of the adrenal glands resulting in the leaching of salt from the body. My GP told me later that my sodium level had been 'on the floor' and I had had an 'Addisonian crisis' which could have been fatal. The condition is rare – the GP had never seen a case – but apparently I share it with Bin Laden, JFK and probably Jane Austen. The answer these days is hydrocortisone for evermore.

I felt relieved that at least the symptoms had been recognized and the condition labelled, but was there a link with the cancer or the radiotherapy? It did seem a remarkable coincidence. The medics doubted a direct causal connection but thought it possible that the stress of the treatment might have allowed a long-suppressed condition to emerge. As with many diseases causation is a mystery. All good things come in threes so I wondered what might drop in next.

2009-10

At the end of December 2009 the PSA was still 0.14. I was just out of hospital with my new Addison's and concentrating on research into nutrition and diet. These,

along with exercise and meditation, or 'serenity', were emerging as the three pillars of a DIY approach to cancer. My hope was that the radiotherapy and my ever-improving diet might somehow combine to bring the PSA down. But in April 2010 it went up to 0.19, in August it was 0.2 and in November 0.3. Still very low but what matters is the trend. At the hospital they explained that after radiotherapy there was often a 'bounce' effect; in my case it only ever bounced up.

2011-12

2011 was worse. In March the PSA was 0.5, in July 1.4, in October 3.7 and by January 2012 it was more or less back to where it had been at diagnosis: 9.5. At the hospital they spoke of the 'doubling time'; if the PSA doubled in three months, intervention should be considered. In two of the quarters in 2011 it had nearly tripled. I drew a graph and found it was a perfect exponential curve – like the tiger analogy impressive but not really something to be proud of. In fact it was depressing. My diet was improving all the time in line with what we were reading, with 'good' foods replacing 'bad' foods, and I walked, danced and cycled regularly, and yet the PSA was heading in the wrong direction at an accelerating rate.

At this point the hospital concluded that the two potential cures, surgery and radiotherapy, both having failed, I had finally relapsed and the disease could now only be 'managed'. This would mean hormone treatment which for all sorts of probably confused reasons I was keen to avoid.

The Doctor

Over the years and especially at this time I relied a great deal on my GP. I am now on my third. What they may lack in specialist knowledge they more than make up in experience, their knowledge of me and my assorted conditions, and simply their availability. They have time for me. The poor hospital registrars had no time to consult my bulging file, they worked from a script and I rarely met the same one twice. The hour or two we always had to wait was evidence of the pressure they were under. With my GP I had a relationship that allowed a dialogue, even, when it came to medication, negotiation. We discussed options outside the script such as diet. We also shared a sense of humour. It's ok to joke about cancer if you

have it; in fact jokes probably have some therapeutic value in themselves, as long as they're good ones.

2012-13

The exponential PSA rise during 2011 slowed suddenly in May 2012 when it scored 10, up from 9.5 in January. The upward curve appeared to be plateauing. I clung to the hope that the diet was at last kicking in. But the upward trend continued albeit at a gentler pace. At hospital visits the pressure was on me to start hormone treatment. Their most persuasive argument was that if the PSA got much higher than 10, especially without an actual prostate gland to call home, the cancer was likely to spread ('metastasize', in the trade). Its preferred destination would be bone, probably the spine. What hormones would do was starve the cancer of its principal fuel, testosterone. It followed that the main side effect would be to remove what was left of my sexuality: hello hot flushes, bye bye libido.

In July 2012 the PSA was 12.7, in November 13 and in February 2013 15.6. The medics I saw at the hospital took to writing letters after my visits, testifying to their efforts to persuade me to start hormone treatment and making clear that my refusal was all that stood in the way. I was simply hoping against hope that my diet and exercise regime would ride to the rescue. Everyone seemed to agree that a PSA of 20 was the end of the line. In May 2013 it was 19.5. A scan appeared to show that the cancer had indeed spread to the lower spine and a rib. I knew the game was up and at the hospital visit on 23 May 2013 I had the first three-monthly injection.

June 2020

That was seven years ago. My cancer has since acquired a kind of volatile stability: the PSA rises steeply until it reaches the mid-teens, a hormone injection fells it like a stone to near 1, it slowly recovers and the process begins again. I am grateful to the consultant at BRI for two, to me, very important things: firstly, he is of the school that believes in 'intermittent' treatment, whereby hormone injections are given only when the PSA rises above a certain level instead of

automatically every quarter; and secondly, for delegating the whole management process to my GP. The 3-month injections have turned out to be effective for 12–15 months at a time. I like to think that this lulls the famously crafty cancer into complacency: why bother creating your own alternative blood vessel support system when you only get knocked on the head once a year? The injection always has a dramatic effect on the PSA. Whether my diet and exercise regime makes any contribution depends on whom you ask.

Repent at Leisure (2)

About five years after the radiotherapy I began to notice signs of faecal leakage, aka skids. This got worse, was investigated with the help of a sigmoidoscopy (an in-depth TV probe where the sun don't shine) and was confirmed as Pelvic Radiation Disease. This is the rather grand title of an unpleasant condition caused in my case by the radiation years before. Basically it had burnt the inside of my bum which was now losing feeling and control. Too late I discovered that this is a well recognised consequence of radiotherapy. The condition has continued to deteriorate. It now needs constant management and impedes many activities, especially out of doors. I was reminded of Hippocrates' advice to his fellow medics in Ancient Greece: 'first, do no harm'.

Diet

Over the last ten years my diet has evolved from dairy-free to full vegan. Everything I eat is plant-based and usually organic. It is broadly what is called the Mediterranean diet, without the animal protein. We get most of our fresh food from organic box suppliers. Happily my reading menu has returned to something nearer normal but I keep up to date with the diet/nutrition/cancer scene through a small number of excellent websites. There is rarely anything random in anything I eat or drink. Whether or not such a diet helps against the cancer, it must be good for my ageing microbiome and therefore for my immune system in general. As Hippocrates also said, 'Make food your medicine and medicine your food'.

Exercise

'Walking is man's best medicine', Hippocrates again. All the literature emphasizes the importance of regular exercise along with diet. My running career ended

about fifteen years ago when arthritis in my left knee put a stop to it. Walking, dancing and cycling stepped up to the plate. Cycling bit the dust literally about three years ago when twice in 18 months I blacked out on the bike, crashed and hurt myself (and the bike) quite badly. The hospital investigated but could find no satisfactory explanation, although they did let slip that I was not the first such case.

Now the Covid lockdown has stopped all dancing and a long walk is difficult to fit in every day, so I have developed a ten-minute fitness routine consisting of running up and down the stairs from the cellar to the attic four times, followed by a few exercises like press-ups and abdominals and stretching with therabands. Twice a day is the aim - not very ambitious really but requiring a surprising amount of self-discipline.

Meditation

Meditation leading to serenity is what much of the literature regards as the third pillar of the DIY approach to cancer. I can't claim to have had much success in this department despite serious attempts at yoga and pilates. I feel ambivalent: part of me fancies a bit of serenity, part of me equates it with inactivity. I seem to need movement to generate thoughtful thoughts. In my youth my best ideas often came during cross-country runs. Each to their own. Obviously I am not against meditation, just not very good at it. My thoughts are in fact mostly centred on my three lads. They have been wonderfully supportive over these twelve years, and in my old age we exchange wit, wisdom and practical help. I suppose you could call that applied meditation.

June 2020

How long have I got? No doctor will say because no two cancer cases are the same. Perhaps it is better not to know; in this instance ignorance may be bliss, especially if one of these days the hormone treatment begins to fail, as I am assured it will, and I am urged on to the next step: the dreaded chemotherapy. The fact is that in twelve years the cancer has yet to cause me any pain or even inconvenience, whereas the treatments have turned my life upside down. On the other hand, without them I would not have discovered what I now regard as healthy eating. It is also true of course that if I had not had the treatments, and

the cancer had continued to grow and probably spread, I would have tortured myself with eternal regret. The cancer was hardly a blessing in disguise but it certainly had a silver lining. Anyway, alongside the orthodox medics I now use a herbalist, who dispenses carefully calculated brews and tinctures.

I do believe I have improved my chances of survival with a diet immeasurably better than it used to be, but then it started from a fairly low base. I also think it helps to have purposeful things to do, and I make sure I always have plenty of them. The quarterly PSA test is a regular reminder of mortality, a check on hubris. Until 2008 I had assumed I would go on more or less for ever. Now I know you're only as good as your last PSA. I am happy to share my experience and the lessons learned along the way with anyone who is interested or maybe in a similar situation, but I am very aware of the danger of becoming a medical bore.

JF

28/6/20