PROSTATE CANCER - My story and my advice for others

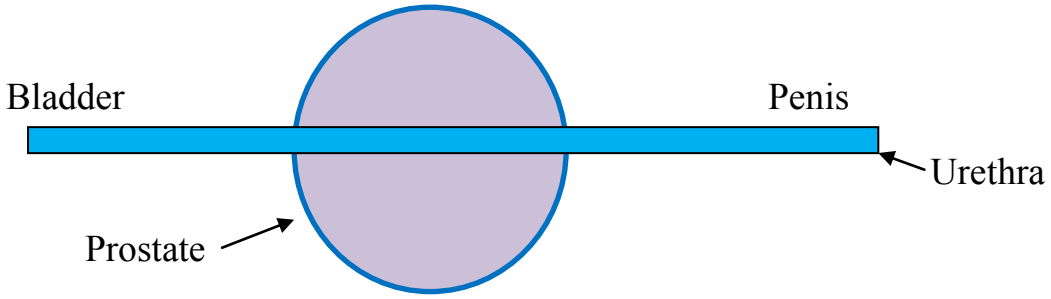
It is now common knowledge that Prostate Cancer is becoming the leading cancer in men. Unfortunately a combination of conflicting advice, and the average men's reluctance to go to their GP over problems 'down there', have resulted in a lot of confusion and a number of men finding out too late, when the cancer has become terminal.

In my case, when I contracted the cancer I had no symptoms and like many men would happily have gone on until it was too late. But my father and brother had also developed prostate cancer so I was aware of the danger and caught it in time. So I have produced this document to describe all the basics, and to tell my story in the hope it will encourage more men to watch out for this cancer.

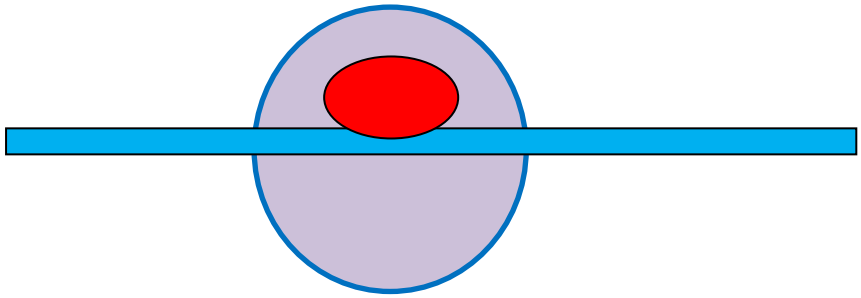
I must add the caveat that this describes my understanding and my experiences. It is not meant to be the definitive guide to the cancer and the treatments. If you want know more there is lots more advice around and people who have are much more knowledge and expertise than me.

First some basics (simplistically):

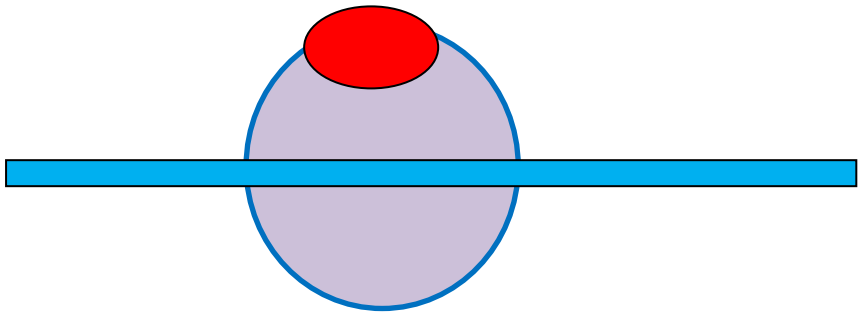
This is a diagrammatic representation of the layout



The prostate is about the size of a walnut, surrounding the urethra which runs from the bladder to the tip of the penis. Now, the usual recommendation for symptoms is to look for general problems with urination. This is because the cancerous tumour is assumed to grow like this:



This will constrict the flow. However, there is no reason the cancer cannot grow like this:



And in this case, not only will you not see any urinary symptoms but the cancer will actually breach the capsule and spread (the technical term is metastasise) into other areas such as the lymph nodes, bladder, liver and the bones. So by the time you feel the pain in your bones it is too late and you are in a terminal situation.

As it turns out, having a father or paternal uncle or sibling having early-onset prostate cancer is a big red flag. Maternal uncles are irrelevant as it seems the genetic fault is passed down through the father (Although I should say the genetic link is not yet officially acknowledged, just seems logical to me). So check your family history.

The initial test is to look for the level of the PSA (Prostate-Specific Antigen) in your blood in nanograms/millilitre. The antigen is produced if there is any damage to the prostate.

The PSA test is getting a bad press as it does give rise to a lot of false positives, thereby leading to unnecessary biopsies. On the other hand there is a much lower rate of false negatives although a low reading is not a guarantee you are clear. In fact, if your PSA level is high they will probably initially put you on a course of antibiotics to make sure it isn't an infection. Basically I would not panic at a single high reading; you need to be looking for a consistent rise in the level.

Might also be worth adding that keen cyclists can often get a high PSA reading, I assume from the bashing the prostate gets from the saddle. So it might be an idea to lay off the cycling before you take the test.

If you do have a high level of the antigen in your blood (>4.0) the next step is for the GP to do a Digital Rectal Exam (DRE), sticking his finger up your rectum. The idea is to feel the size, shape and consistency of the prostate; if the cancer is close or outside the capsule then he can feel it. If it feels perfectly normal then it means that any cancer should be fully contained. Not fun, although try and have an empty bladder before it is done to avoid 'accidents', but not painful, but at this stage you

have to accept that if all this is going further then your dignity has to be checked in at the door and you will have to get used to 'flashing' lots of people and generally being placed in undignified positions while doctors and nurses examine your nether regions. The only alternative is to bury your head in the sand ☺

The next step in the process is the needle biopsy, where an instrument containing a 'gun' and an ultra-sound camera is pushed a couple of inches into the rectum. Again, not painful, they use lots of lubricating jelly and a local anaesthetic, it just feels very odd. They then use the ultrasound to guide the gun and fire up to 20 microscopic needles into the prostate (Quite impressive when you think it is the size of a walnut) to take samples right across the full width. Again I should emphasise this is nothing to be scared of, it's not painful, just unusual.

However, it does carry its own risk, as you are basically firing a needle through a heavily populated bacterial area into the prostate, so it can give you an infection. Another reason why doctors are reluctant to do it, so again you have to balance risks.

A pathologist will then examine all the samples and will determine if there is a tumour present, and if there is, will allocate what is called the 'Gleason Score'. This consists of 2 numbers, in each case using a score of 1-5, where:

1. No trace
2. Minimal
3. Slow growing cancer
4. Fast growing cancer
5. Very aggressive cancer

The first number is the type of the majority of the cancer cells in the tumour and the second number is the next most common type. Now, in practice, they don't normally bother with 1 & 2; you will be given the all-clear. The first stage of the real thing is when a cancerous tumour is present but is all of the slow growing variety, in which case your Gleason score will be 6 (3+3). The next stage would be if the majority of the cancer is slow growing but there are areas of the faster growing type, in which case your Gleason score will be 7 (3+4). If it is all fast growing then it will be 8 (4+4) and so on. Obviously the higher the score the worse it is going to be.

As a general rule, if you have a Gleason Score of 6 (3+3) then there is no panic. You do have cancer but you might be able to live with it and you have time to consider all the options. If you get a higher Gleason Score it will mean that there is a more

aggressive type of cancer present and you really shouldn't ignore it. In this case you should start considering the options straight away.

Like many things there are lots of other 'buzzwords' that you may hear during your discussions. And different people use different definitions to describe the cancer .The ones I am aware of are:

a. **Localised.** This means the tumour is fully contained within the prostate capsule

b. **Locally Advanced:** This means the tumour has just breached the capsule but not by much.

c. **Metastatic:** The cancer has moved into other parts of the body.

You may also hear the cancer being described in terms of stages (and sub-stages). As far as we are concerned we have

a. **Stage T1:** The tumours are very small, almost microscopic.

b. **Stage T2:** The tumour is completely contained and can be:

    a. **T2a:** The tumour is in less than half of only one lobe of the prostate

    b. **T2b:** The tumour is on more than half of one lobe.

    c. **T2c:** The tumour is in both lobes

c. **Stage T3:** The tumour has just broken thorugh the capsule

d. **Stage T4:** The tumour has spread to other organs.

So you can see that Stage T2 is equivalent to Localised, T3 is equivalent to Locally Advanced and T4 is equivalent to Metastatic.

So once diagnosed you have to decide on a course of treatment. There are lots around, and the first thing that will happen is that each of the two specialists (Urology for Surgery and Oncology for Radiation) will discuss the pros and cons of each type. I found them both very helpful and didn't find either of them giving me the hard sell, both of them emphasised it would have to be my decision and all they would do is make sure it was an informed decision.

Basically they are the 4 options, some of which have some sub-options:

A. **Active Surveillance**: It is generally accepted now that most men will eventually get Prostate Cancer; it is a genetic flaw we haven't managed to breed out yet. But many of the sufferers will never even know and it will have no effect and they will eventually die of something else. So, with all the risks and side effects of the treatments, there is a school of thought that an early-stage cancer should initially be left alone and just monitored by regular PSA tests and DREs. This is known as Active Surveillance.

B. **Radical Prostatectomy**. This is the surgical option to remove the whole prostate and hopefully all the cancer. There are 3 sub-options:

a. **Old-school**: This is the normal surgical operation where the surgeon makes an incision from just below the navel down to the top of the pubic bone (5-6") (or in through the area between the scrotum and the rectum) and then gets in there and sorts it out. All done under a general anaesthetic and you would expect to stay in hospital for 3 days.

b. **Laparoscopic**: This is the 'keyhole' method, where the surgeon makes 5 small (1-2cm) incisions, 2 for cameras and 3 for surgical tools, then does the identical operation but using the tools and watching on a screen. The advantage here is the hospital stay is normally just overnight, and you should heal quicker.

c. **Robot-Assisted Laparoscopic**: This is the same operation but the surgeon carries it out remotely, sitting in front of a screen operating a console. Bit like a video game.

C. **Radiation Treatment:** This is the non-invasive procedure and can be done by 3 different methods:

a. **External Beam Radiation:** This is where a 'ray-gun' is aimed at the prostate area, the basic idea is that it kills of the tumour. It's a long-winded procedure that involves a 15-min visit to the hospital, 5 days a week for 7-8 weeks.

b. **Internal Radiation (Brachytherapy)**: In this method some 25 radiation 'seeds' are placed inside the prostate to try and kill the tumour.

c. **Hybrid**: I was actually offered a method I hadn't heard of before, which involved planting some metal bits into the prostate and then using the External Beam Radiation for just 3 weeks.

D. **Hormone Therapy:** Under this treatment you are given oestrogen. The logic of this is that the tumour needs testosterone to grow, so if you can reduce the male hormone and increase the female hormone then the tumour and the prostate will shrink. This treatment is often used in conjunction with the radiation treatment, to shrink the prostate first before the radiation treatment is started.

There are also other procedures under test, such as High Intensity Focussed Ultrasound (HIFU), but you would have to specifically request to be included in the trials, and there is no guarantee of success.

You will need to research the pros and cons of all these methods before you decide which to go for, although it is worth pointing out that the cure/survival rate for all the procedures seems to be identical, which is why none of them have become a 'front-runner'.

It is also worth noting that over and above the risks normally associated with a general anaesthetic all the procedures carry side effects:

Urinary Incontinence: When you have surgery they will actually remove about an inch of the urethra and then sew it together afterwards. You will wear a catheter for about 2 weeks while the join 'heals', but after removal you will find you have little or no control. This can last from a few weeks to 6 months, with a small proportion of men never recovering full continence. The radiation treatment will also have a similar effect, purely because as well as killing the tumour you are also damaging all the healthy cells around that area.

Bowel Incontinence: Mainly associated with the Radiation method for the same reason. This is unusual in the surgical method unless the surgeon makes a mess of the operation.

Impotence: The nerves (Cavernous) that control erections pass either side and close to the prostate. When the prostate is removed (or bombarded with radiation) there will always be the danger of damage to the nerves. And if the cancer has spread outside the capsule and more tissue has to be removed then it is most likely the nerves will have to be removed as well. The default for the surgeon will normally be a 'nerve-sparing' procedure, but obviously he will not know if it can be done until he is actually in there.

Infection: Only associated with the surgical operations, it will carry the same risk of infections as any other major operation.

Discomfort: The female hormone treatment has the unfortunate side effect that you will start to develop breast tissue, and apparently that can become quite painful. So far I have no individual knowledge of that as my prostate was already on the small side and did not need shrinking.

Having said all that, you may find some of the decisions are taken out of your hands. For example, if you have ignored my advice and the cancer has now moved into other organs then surgery is not an option; you will have to go down the radiation route. And if you are deemed to be too old for surgery or have other problems that make surgery a risky option they will again recommend you have radiation.

So do your own research, ask all the questions you can of the professionals, talk to other suffers… There is a huge amount of information and help out there. A good place to start is at http://prostatecanceruk.org/information/our-publications Lots of useful info.

THIS IS MY STORY

Now in my case I knew my father, uncles and younger brother had all developed the cancer, so I was almost certainly going to get it, so I insisted on having PSA tests once I passed 56. Have to admit that in my case the GP did not object, she also thought it was a good idea. Initially the level sat around 2-3 so I was unconcerned. Then, at the end of 2010 it passed 4.0, which is normally the trigger point where further investigation is required. But in my case nothing was said and I didn't worry too much as I assumed there was a fair safety margin built into the guidance (typical male attitude unfortunately).

Then a year later it passed 5.0 and at that point we decided it was time for the first step, a Digital Rectal Exam (DRE). The female GP declined to do it ☺ so it was carried out by a different GP and he said it was the most 'normal' prostate he had ever felt, so I wasn't worried and we left it alone.

At the end of 2012 the level had climbed to 6.0, and this time a red flag was raised so I was initially put on a course of antibiotics to see if it was an infection that was causing the trouble. And at the next reading it had dropped to 5.8 so again I wasn't too worried and we left it alone.

But in mid-April of 2013 it had climbed back up to 8.0 so the GP and I decided it was time for action. The GP referred me to a specialist at Grantham hospital. In fact I then heard nothing for 3 months and went back to the GP to ask what was going on. I have no idea why nothing had happened, but I was very quickly given an appointment at the hospital. The specialist carried out another DRE and said it felt perfectly normal, and in the absence of any urinary symptoms, was not too concerned. But he did recommend a needle biopsy, to which I agreed. Again it was a couple of months before I was called forward for the biopsy, but to be fair, no-one was very concerned about my condition and this time scale is well inside the official NHS guidelines for waiting times.

So I had the needle biopsy and it was recommended I have an MRI as well. I don't know if this is standard procedure, or whether the doctor doing the biopsy saw something on the ultra-sound, but I picked up a cancellation the following day and had the MRI.

A couple of weeks later I was given another appointment for the specialist to hear the results, and it turned out that I did have cancer, with a Gleason score of 7 (3+4).

There was a tumour in the left lobe, about 20% the size of the prostate and some of it was of the fast growing variety. The good news was that the MRI had also showed it and confirmed it was contained within the prostate capsule.

In some ways this was good news, as I knew I was going to get the cancer eventually. The Gleason score meant that Active Surveillance (which I had effectively been doing anyway) was not an option anymore and something had to be done. The fact I was still relatively young and fit, and the cancer was fully contained meant that both surgery and radiation were valid treatment options. The only slight caveat to that was that my prostate was surprisingly small and right on the minimum limit for the Brachytherapy (internal radiation) treatment.

After the interviews I opted to go for the old-school radical prostatectomy. Now this is a very personal decision and you need to do lots of research before you make your own decision. So, without wishing to influence you, this is how my thought process worked.

a. Both Ruth and I were very impressed with the surgeon. He came across as very professional and helpful. The general advice is to find a surgeon who has already done 1000 operations so he isn't practising on you. I was lucky enough to find one. You may not be so lucky.

b. The surgeon said he would be quite happy if I opted for laparoscopic surgery, but there were no qualified surgeons in the Lincoln Trust so I would have to be referred to Addenbrooks hospital in Cambridge or Guys hospital in London.

c. We discussed the fact that his 'old-school' method would mean a large incision whereas the keyhole needed only small ones, but he reassured us that his incision would be small and he prided himself on his stitches (he was true to his word, the scar was only 4" long and healed very quickly). He also pointed out, quite reasonably, that 5 incisions, however small, gave 5 times the opportunity for infection and said he had seen some very poor cases recently.

d. Importantly, if you opt for the radiation treatment then you can never have any follow up surgery. Apparently the radiation treatment creates so much scar tissue that surgery would not subsequently be possible. On the other hand, if you opt for surgery and they leave a bit of the cancer behind, then you can still have radiation treatment afterwards.

e. The external radiation treatment takes 2 months of daily visits 5 times a week. For me it would have to be done at Lincoln, which was an hour drive away,

whereas Surgery would just be 3 visits. I accept this is a very shallow viewpoint when you are talking about the rest of your life, but subconsciously I could never forget what a hassle it would be to do all that driving.

f. As I have already said, I was right on the limit for the brachytherapy (internal radiation) so I never really considered that.

g. Finally, external radiation carried the risk of bowel incontinence. I reckoned I could cope with urinary incontinence but I dreaded the thought of bowel incontinence.

So, my final decision, taken relatively quickly, was to opt for the old-school radical surgery. But, as I said, I don't want to influence any decision you may take, and I must emphasise that a large part of the decision revolved around me finding a very experienced surgeon who I felt I could trust and put my life in his hands.

So, on the morning of 30 Dec 2013 I went into hospital. I was called forward at 11:30 to see the anaesthetic team, and as usual, they said "Just going to give you a sedative to make you drowsy" and the next thing I remember is waking up in the recovery room with the surgeon looking at me and telling me it all went very well.

I must have dozed off, as the next thing I remember is waking up in the ward at about 18:00. I had an oxygen mask on, a morphine drip into my left hand, a catheter (a tube that is fed through the penis, up the urethra to the bladder) feeding into a bag hanging by the bed on the left, an intravenous automatic anaesthetic drip feeding into my groin from the right side of the bed, and a drain from next to the incision feeding another bag hanging down on the right side of the bed. I looked like I was in intensive care! However, a few minutes later the oxygen mask was replaced with one of those tubes with 2 small tubes that sit in the nostrils. That was much more comfortable.

I was very impressed with the overall pain management system. Basically, the intravenous feed into the groin automatically fed a controlled amount of anaesthetic. If I felt that wasn't enough there was an override button that I could press to add a bit extra. Then the morphine drip feeding into my left hand was a PCA (Patient Controlled Analgesic) system. That meant I had a trigger near my hand where I could inject some morphine if the pain got too bad. Finally the nurses gave me paracetamol tablets every few hours. What actually happened, as a tribute to the surgeon I think, was that I never needed to override the automatic system, and I never needed to use the morphine drip. And I came off the paracetamol tablets after 36 hours and the automatic system was removed just before discharge. At no time did I

feel any pain apart from having a sore throat from the oxygen tube down my throat that they had used in the operation.

Spent a fairly good night and next morning the oxygen was removed and I was encouraged to get out of bed and sit in a chair. I was given some support stockings to wear to prevent DVT. In the morning the surgeon came around with all his entourage and after some discussion told them to remove the PCA morphine drip as it was obviously not needed. And he said I had recovered so quickly I could be discharged to following day rather than stay in for the full 3 days. He confirmed the operation had gone very well and they had managed to save one set of nerves (that is all you need for an erection). Apparently the other set of nerves were glued to the prostate and had to come out. They had also removed some lymph gland tissue as a precaution.

Unfortunately the following day was New Year's Day and no doctors appeared for the morning rounds. The surgeon popped his head in just after lunch and was very annoyed to find I was still there. So there was then a rush job by the nurses to get me out before close of play. The anaesthetic drip in the groin was removed, as was the drain from the wound. So all I had to show for the operation was a nice clean dressing and the catheter. This has to stay in to keep the urethra open where it was cut and re-joined, while it healed.

So I was discharged and sent home with enough catheter supplies to last a few days. The following day I had a huge delivery of more catheter supplies, enough to last for months, and a few days after that, about 350 incontinence pads. All very impressive.

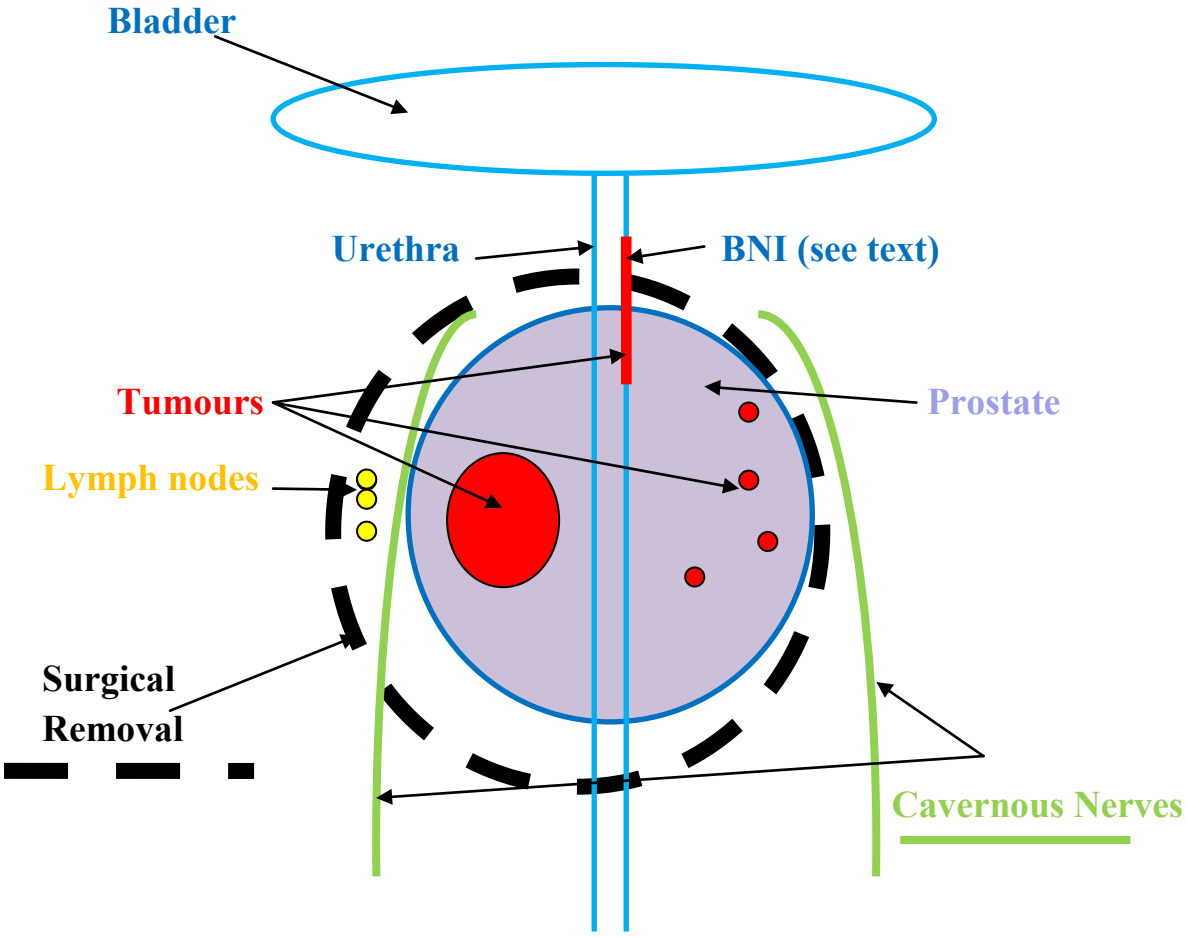
Then the NHS made its one and only mistake in my opinion. The plan was always to get the catheter removed after 2 weeks, but Lincoln only did that clinic on Tuesdays and the clinic in 2 weeks' time was already fully booked so I was given an appointment 3 weeks away. As you would expect I did not accept that arrangement and after a sharply worded (although I hope still respectful) e-mail to the nurse in charge it was arranged I could attend Grantham hospital at the 2 week point and have it removed 'off-the-books'. Needless to say I was glad to get rid of it. It isn't painful; it just becomes annoying having a bag half full of urine flapping around your legs.

Then, a week later I was unexpectedly summoned to see the specialist to discuss the histology (post-op analysis of the removed tissue). I guessed that all was not well, and when I got there he told me that the cancer had actually been rather worse than they thought, with traces in the right lobe as well as the main tumour in the left lobe.

And I also had what is known as Bladder Neck Invasion (BNI) where the cancer has started to move into the urethra and the point where it leaves the prostate.

He reassured me it was not life-threatening, but may mean that the cancer will reoccur in the future and in that case would require a radiation follow on treatment. The first indication would be the PSA test I would have before the next visit. If it was below 0.05 then that would be deemed a success, although my PSA level would still be monitored regularly for some years. Above 0.2 meant that I would definitely have to have a course of radiation.

This diagram explains what happened to me



The needle biopsy had picked up the major tumour in left lobe, confirmed by the MRI Scan, so the prognosis was that the cancer was fully contained. This was also backed up by the Digital Rectal Exam (DRE) where the surface had felt smooth.

As shown, the Surgery removed the prostate and the left set of nerves, along with some lymph gland tissue. The right set of nerves were preserved using a procedure known as unilateral nerve sparing.

So far so good, but then as I said earlier, the histology tests on removed tissue found other small tumours in right lobe and cancerous tissue at bladder neck. This is known as 'microscopic bladder neck invasion (BNI)' and is basically impossible to predict before surgery (occurs in about 20% of men). So there is an unknown amount of cancerous tissue remaining on the urethra.

There is no way of predicting what the long-term effect of this will be, I will just have to wait and see. It is just unfortunate that we cannot rule out the cancer coming back.

Incontinence

The operation will all be over fairly quickly, the catheter will be removed 2 weeks later and by then the external healing process will be almost complete. It's still a good idea to take it easy for a few weeks as you need the muscle to be fully healed as well. I started exercising gently after 3 weeks, working up until I was back to full speed after 6 weeks.

However, now comes the worst part as far as I am concerned. After the catheter is removed you will have absolutely no control over the bladder and will have to wear nappies and/or incontinence pads. The good news is that over 90% of men eventually recover full continence, but it can take up to 6 months. Although I could see a gradual improvement over time I still found it very frustrating. The important thing is you MUST carry out pelvic floor exercises to bring those muscles back to normal. Plenty of ways to do them recommended on the Internet. Personally I used 10 repetitions of 10 second 'clench' and 10 second 'relax', followed by 10 repetitions of a short tight 'clench', all controlled by a Timer app on my iPhone.

In fact it is recommended you actually start during these exercises in the weeks leading up to the treatment so they are in the best condition possible before you start.

The recovery process will be completely different for each person, but just as an indication, this is what happened to me:

Operation:

Week 2 : Catheter removal: No control at all. I experimented with nappies and pads over the first few days. I eventually found the best solution was to wear a nappy and also use the pad inside, up to 4 a day. The pads are rated at 150ml, the nappies are rated at 1.5 ltrs. I am finding I am producing about 2 ltrs a day.

Week 3 : Very little improvement, not managing to hold anything in at all. Very depressing.

Week 4 : Starting to see an improvement at night, with little or no leakage when lying down, although finding it difficult to hold it when I get out of bed. Also seeing an improvement when sitting down, but again struggling to hold it when I stand up. I'm still not getting any 'bladder full' indication.

Week 5 : Still wearing the nappies and pads, but the nappy is now invariably completely dry. So I will soon revert to just using underpants and pads. I am occasionally getting right through the night, again dry, but maybe losing 5% while going from bed to loo. And am now beginning to feel a 'bladder full' indication, which is good news.

Week 6 : Out of nappies now and just using the pads to catch the drips as I don't have full control at the beginning and end. So good progress and I now feel that if necessary I could happily live at this stage of recovery if it did not improve.

Week 7 : Not a good week. I am now getting the 'bladder full' message, but up to 10 times a day and producing little urine. And I had one day when for 3-4 hours I was getting the feeling but could not urinate, and the pain was enough for to wonder if I should go to A&E as my urethra might be blocked. However, eventually I managed to go and after that I was back to the normal feeling and regular visits again. I think what I was experiencing was 'bladder spasms', not recommended. It may be a coincidence but that day I had only 2 cups of coffee between 06:00 and 14:00 so maybe it was dehydration that caused the spasms? Since then I have made sure I drink sensibly and the problem has not reoccurred.

At this stage I had my first PSA test. The result was initially given to me by the GP's receptionist as 0.05, which was VERY frustrating. It wasn't the zero/undetectable I hoped for, although is well below the 0.2 trigger point that would show I needed additional treatment.

So I had a return visit to the surgeon to discuss it and it turned out the reading was actually 'less than 0.05', which is the lowest possible reading they are allowed to give because of the measurement limitation. So actually mine was 'undetectable'. Good news, so all I have to do now is have a PSA test every 6 months to monitor progress. Again we are not looking for a single high reading, as that can be an anomaly. We are looking for a gently climbing reading and action will be taken once it is through 0.2.

During the visit we discussed the bladder spasms and he said it could be because of a number of reasons. It could be an infection, it could just be the healing process or it could be scarring causing a restriction in the urethra valve. Apparently up to a third of patients suffer these problems, so it isn't unusual. So first step was to test for infection, and also do an ultra-sound scan to see if I was actually full voiding the bladder.

It turned out I wasn't fully emptying the bladder so the nurse prescribed me a drug that should relax the bladder sphincter muscle to assist in emptying the bladder.

Week 8 : Unfortunately not much improvement. It definitely looks as though my urethra has a constriction as a result of the surgery. I shouldn't be surprised really, as up to 30% of patients will experience this problem. As the nurse was on annual holiday I went to my GP. He also suggested an infection and took a urine sample as well as suggesting I double up on the 'relaxing' drug and see what happened. This very quickly solved the problem and I now have no problem emptying the bladder, with a reasonable flow rate. So I am back to trying to control it again. I find I can hold it if necessary but haven't regained the involuntary 'holding' so need to work on that.

Week 9 : The results of the urine sample showed I did indeed have an infection, and one that was resistant to a number of antibiotics, so I was put on a course of a special antibiotic. Also, after a discussion with the hospital nurse we decided it was time to register me with the local incontinence nurse as I was obviously not going to become continent on the short term.

Week 10: Signs of improvement. I am now sleeping right through the night, which makes life bearable, and also managing to hold in amounts up to 100ml during the day. Light at the end of the tunnel ?

I will keep this up to date to hopefully describe the improvement.

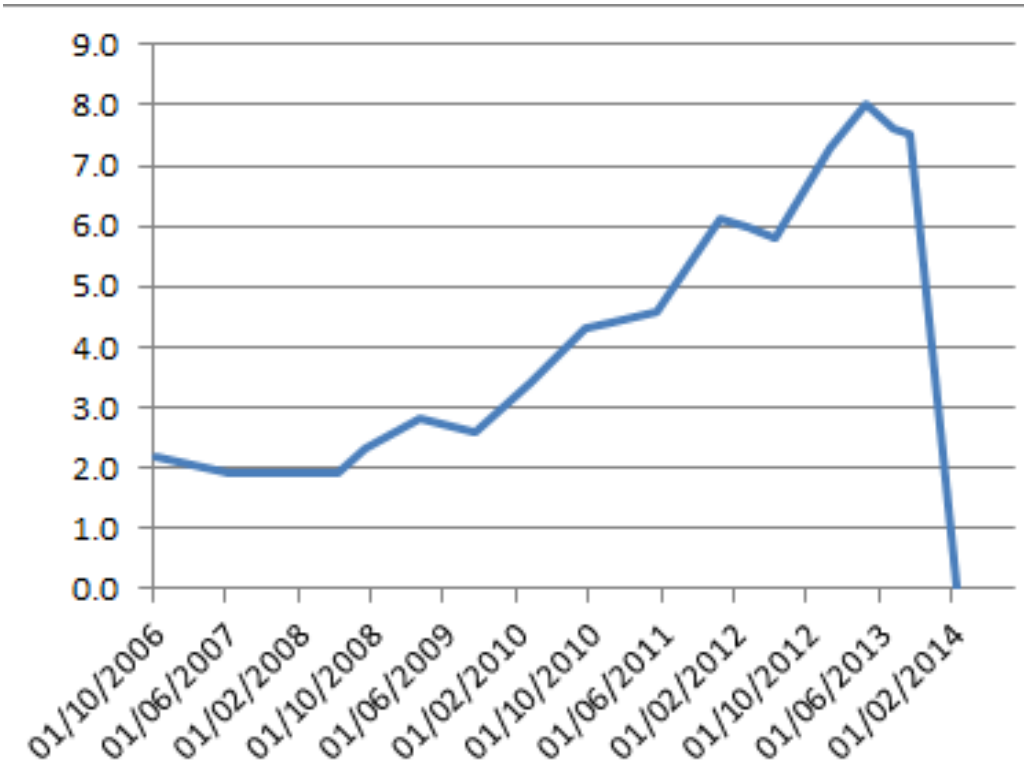
Erectile Dysfunction

As expected there is no sign of life in that department yet. But regaining this function could take up to a year so I will just have to be patient.

Lesson Learned

The last thing to discuss is why did it get to the stage from such a promising start and why wasn't the operation 100% successful? What did I do wrong?

Remember I started having my PSA test measured back in 2006 and this is a plot of the results.



The official 'trigger' point is when the PSA climbs above 4.0, although not as a one-off reading, as there are various other things that can cause an increase. As I said, when it passed 5.0 in mid-2011 I had a DRE which showed there was no problem and when it passed 6.0 in early-2012 I was put on a course of antibiotics to make sure that wasn't causing it. It had no major effect, but unfortunately there was no follow on check.

Like most men I had decided that a level of 4.0 was too low and scare-mongering, so I had ignored it. It wasn't until the level when through 7.5 in early-2013 that the GP and I decided that action was required. In fact it was actually a further 6 months before I was given the biopsy, but I can't blame the doctors for that as I had assumed it would be OK so was in no hurry. As a result I didn't push it.

So, hindsight is a wonderful thing, but it is obvious now that I should have seen the writing on the wall and had the biopsy when I passed about 6.0, some 6-8 months

before I actually had it. The only caveat to that is the result at that stage may very well have been a Gleason score of 6 (3+3), and then I would probably have been advised to go onto "active surveillance" and action would not have been taken until my Gleason score got to 7 (4+3), about the time I actually had the biopsy. So it may have made no difference, as the BNI could not be identified pre-surgery but on balance it would probably have been better to have the biopsy earlier than I did.

And I should not have been so relaxed about the long timescales. After being referred to the specialist I waited 3 months before asking the GP why I had not heard anything, I should have chased it up much earlier. Similarly I should have chased up earlier why the biopsy appointment was not happening, and not waited 3 months. It is worth noting that the 'official' timescales laid down for the NHS is 82 days, although this is overruled if the problem is urgent. I suspect mine was not labelled as urgent.

So that is my story, I hope you have found all this helpful. Feel free to get in contact if you need any more information. I found it invaluable to have someone to discuss everything with and I am quite happy to perform that function for anyone else.