

A PERSONAL EXPERIENCE OF PROSTATE CANCER

October 2007 to April 2008

| | page |
|---|------|
| Introduction | 2 |
| How I discovered my problem | 2 |
| My diagnosis | 3 |
| Treatment options <ul style="list-style-type: none">• Active Surveillance• Radiotherapy• Surgery | 4 |
| How I made my choice of treatment | 5 |
| Leading up to my admission | 6 |
| The operation and hospital recovery period | 6 |
| Back home first week | 8 |
| Back to hospital for cathetar removal | 8 |
| Back home for good - convalescence | 8 |
| Post operative consultation and results | 9 |
| Conclusion and reflections | 10 |

Introduction

I have decided to write this account of my experiences before, during and after my decision to undergo Laparoscopic Radical Prostatectomy for early stage prostate cancer. In particular how I dealt with my diagnosis, how I made my choice of treatment and how it affected me. My motivation was that, despite a considerable amount of literature available on the subject and the excellent support given by all the medical professionals with whom I have come into contact, I felt that something was lacking. Once I had read numerous brochures and online papers and had a number of discussions with the medical team, I still had many questions. I read numerous online case studies on various cancer web sites but always wished they had gone into more detail of how it would affect me personally on a day to day basis.

I am aware that other peoples' experiences will be different in the way they cope with the situation and their recovery period. I feel my experience has been very positive and hopefully what follows may be of help to others in finding their way through what could otherwise have been a very traumatic period in their life.

How I discovered my problem.

I am 56 years old and in very good health. I keep myself fit with three visits to the gym and a swim each week. I also go hill walking in Derbyshire at the weekend with my wife as often as possible. I am an architect and have a job that is challenging. However, a good diet, lifestyle and general approach to life allows me to cope well with any stress.

Prior to this I had not experienced any urinary problems. In late September 2007 and without any prior warning or obvious reason, I developed a urinary infection. This was successfully treated with antibiotics by my GP over a two week period. However concern over my PSA level lead to a rectal examination of my prostate. Although the gland appeared relatively small, there was evidence of some harder tissue. I was referred to Stepping Hill Hospital in Stockport to see a Consultant Urologist. My appointment was made for approximately two weeks later.

During the appointment a further PSA blood test was taken together with a further rectal examination – I would describe the examination as uncomfortable rather than painful.

As result of the findings I was recommended to undergo a trans-rectal ultrasound and biopsy at a further appointment approximately two weeks later. On the day of the procedure I was apprehensive but I was aware that

the staff were skilled in techniques of relaxation and distraction. I am a passionate rugby fan and will discuss my sport anywhere at anytime. However discussing the recent world cup final whilst undergoing a rectal examination is an experience I will not easily forget. Again I would describe the procedure as uncomfortable rather than painful, with the brief exception of a slight sting when the biopsies are taken.

My follow up appointment to receive the results of the biopsy was made for two weeks later.

Both my wife and I are fairly pragmatic and consequently tend not to worry about what may not happen. Similarly we deal positively with the outcome of events when they are known. As a result we decided not to research the possible outcome of the biopsy at this point. I remained very calm throughout this waiting period and managed not to feel concern. In hindsight I may have been in slight denial although I don't think so. On the morning of the appointment to receive the results, as it got closer to the time of the appointment, I admit to some mild apprehension.

My Diagnosis

I received the diagnosis that the biopsies had revealed evidence of early stage prostate cancer with a PSA level of 3.7 and a Gleason Score of 7. At this point I think my brain went into a state of suspended animation as I did not follow clearly the comprehensive range of treatment options outlined by the Consultant. I felt disorientated and uncomfortable in what was a clinical and impersonal consulting room. This I felt was not an ideal environment in which to receive such news.

What followed almost immediately however was excellent. I was introduced to my Urology Nurse Key Worker whose role is to guide, support and generally hand hold both myself and my wife through the next stages of the process. We were shown into a comfortable office with a totally opposite ambience to the consulting room. We were given the time to take a deep breath and reflect on what had just been presented to us and to ask as many questions as required. Over the next few weeks this relationship developed into an excellent support system where help and information was available either face to face or at the end of a telephone.

This became invaluable as it was made clear to us that, while all the information on the various treatment options would be made available to us, the decision on the choice of treatment would be down to us. Even after 24 hours reflection my concern at that point was how would I be able to make the right choice?

Treatment Options

I was initially offered four treatment options which subsequently increased to five. By this time my wife had started researching through various internet sites and reading the excellent handbooks issued by the Health Authority. It took me about a week to get myself into gear and start my own reading since until then I think I was not so much in denial as in a state of disbelief.

I was informed that, since my cancer had been detected at a very early stage, there was no urgency to make a decision and that, in effect, time was on my side. From the very start we decided that all available options would receive equal consideration.

Active Surveillance

The positives of this option appeared to be no more than postponing the choice of treatment to a time sometime in the future. The negatives however were that firstly the cancer cells were there, were not going to go away and at best would progress at a slow and non-aggressive rate. Secondly it would be necessary to have regular PSA checks and possibly further rectal examinations every few months for many years and possibly for the rest of my life with the consequent stress of waiting for the results of these tests. Thirdly I was young and healthy enough to undergo either surgery or radiotherapy.

Active surveillance as an option was therefore dismissed.

Radiotherapy

Within a week of my diagnosis I had received an appointment with a Consultant at Christie Hospital to discuss the radiological options. Despite passing Christies many times over 40 years I had never been inside and was apprehensive about what to expect. Would everybody I saw there look so ill that it would upset me? This was balanced by the fact that it had a world class reputation.

I immediately felt welcomed and cared for by a highly professional team. During a two hour visit I was questioned at length and briefed on the two radiological options available: external beam radiotherapy or brachytherapy. Finally, a consultation with a Brachytherapy Coordination Nurse, operating in a similar role to my Urology Key Worker Nurse, filled in much of the detail of how each option would affect me.

Prior to my visit to Christies I was still considering both options, although on balance I was tending towards brachytherapy due to its shorter treatment period and my suitability to undergo an anaesthetic. By the time I left Christies

and without them being explicit, it appeared clear that brachytherapy was the most appropriate radiological treatment for me.

External Beam Radiotherapy as an option was therefore dismissed.

Surgery

At a further visit to see my Urology Key Worker Nurse, to review the information to date and discuss the option of Radical Prostatectomy Surgery in more detail, a fifth option was suggested - Laparoscopic Radical Prostatectomy. This would involve a longer operation but with a shorter recovery time. An appointment was made later that week to see the Consultant Surgeon who could carry out this procedure.

To my surprise, rather than just discuss this particular option, the Consultant talked us through all the options considered to date and our reasons for either dismissing or still considering them. This was undoubtedly the most productive consultation to date, due partly to the sensitive way the Consultant guided us through the discussion, but also as by then we were sufficiently knowledgeable to ask the right questions.

I cannot stress enough the need to familiarise yourself with as much available information as possible as a patient. By then we had both read all we could but also discussed widely with family friends and colleagues.

I now had the information necessary to enable me to make this difficult decision.

I left the hospital that afternoon knowing the following three things. Firstly my choice was reduced to two options: brachytherapy or laparoscopic radical prostatectomy. Secondly there was little or nothing to choose between them. Thirdly I would make my decision that day.

How I made my final choice

To help me make my treatment choice I considered the following:

- Both involved surgery with a general anaesthetic for was a suitable candidate.
- Both involved potential bladder and bowel problems – variable but in most cases temporary.
- Both involved infertility – not an issue as I had a vasectomy some years ago.
- Both involved potential impotence – in most cases temporary.
- Both involved either a short time in hospital or a short treatment period.
- Both appeared to have similar possible short or long term effects on my lifestyle.

- Both ultimately carried risks but by that time I had sufficient trust in the skill of the professionals who would undertake the treatment.

After discussion with my wife we concluded that we could not objectively choose between one option over the other. At that point it could literally have come down to the toss of a coin. We also agreed that the final decision should be mine. I sat in a coffee shop in Manchester by myself for a couple of hours and reflected on my unexpected journey over the last couple of months and all that I had learnt. and made my decision to have a laparoscopic radical prostatectomy. Ten weeks had passed since my first visit to the GP and a further two weeks since my diagnosis.

Leading up to my admission

At this point my Urology Key Worker Nurse took over and within ten days I had been given a provisional date of 4th January for my operation. In addition I had a date of 14th December for the pre-operative assessment clinic. The latter was a short visit of just under two hours, involving a detailed set of questions on medical history and lifestyle, a blood test, blood pressure, chest examination and an ECG. Once assessed as satisfactory for surgery the operation date was confirmed.

Throughout December I used the time as constructively as possible. It was not clear at that point how long I would be convalescing. I had received excellent support from my employers so simply had to delegate work to my colleagues.

Mentally I was surprisingly relaxed. I think my lack of anxiety was due to the fact that having put all the emotional effort into making the right decision I was now ready to get on with it.

The operation and hospital recovery period

I was due to report to the ward at 7.00am on the day of my operation Friday 4th January. Having been mentally prepared for a wait, to my surprise I had been checked in and changed by 8.00am and soon after was wheeled off to the anaesthetic suite.

I understand I was in the operating theatre for approximately four hours and that the procedure was carried out successfully without complication.

I regained consciousness back in the ward between 2.00 pm and 3.00 pm. Throughout the afternoon I remained very drowsy and whilst aware of my visitors and the coming and going of the staff, did not feel able to interact with them. As the afternoon wore on I felt mild pain as the anaesthetic started to wear off. I felt some confusion as I had been told that I must ask for painkillers

but also that they would make me constipated. My instinct was to trust the staff and painkillers were both needed and gratefully received over the first 24 hours.

I also felt sick which I understand is common. My concern here was retching on an empty stomach and the resulting strain on an already painful area of my body. I was given suitable medication to help the nausea.

I slept very lightly that night and struggled to get comfortable. Early in the morning I was moved to a more upright position in the bed and found the pull on my stomach so painful that I briefly cried out loud. At the same time the kindly and well meaning nurse told me that I really should try and get out of bed that morning and sit in the chair.

At that point feeling tired, sick and generally as if I had been hit by a truck, it seemed the last thing I wanted to do. With help however I managed to get into the bedside chair and to my surprise within 10 minutes my whole body felt better and my spirits lifted. I even managed a very light breakfast.

At this point my neighbour in the next bed who had under gone the same operation 24 hours ahead told me that the recovery rate at this point seems very fast and that by tomorrow morning I would both be mobile and feeling much better. I found this encouragement very supportive and I think it was at this point I decided to document my experience for the benefit of others.

Throughout the rest of the day I started to move very gently around the bed taking the advice of gentle exercise. By the time of afternoon visiting I suggested to my wife a walk to the end of the ward. Very slowly I managed it without too much discomfort and 20 minutes later repeated it. This was a mistake as on returning to my chair felt sick and dizzy and my blood pressure fell rapidly. However 20 minutes later and after a little oxygen I was fine again. I was subsequently told that I was being too optimistic and had done too much too soon.

By the evening I felt much better, regained my appetite and ate a light meal. I found concentration difficult and could not read for more than a few minutes. By now the intravenous fluid drip had been removed and I was drinking regular quantities of water. I was also getting used to the strange sensation of my catheter and its regular emptying.

A much better and more comfortable night lead into Sunday morning. The day was essentially more of the same with steady improvement in mobility, appetite and general attitude. I stopped having pain relief during the morning without undue discomfort. I had not since before admission had a bowel movement which I understand was normal. However trapped wind was becoming a problem with a painful and slightly distended stomach. Peppermint water was given and this helped. Also during the day my drain tube was removed without pain or discomfort. Generally by the end of the day I was progressing well and was moved into the adjacent convalescent ward.

By this time I was slow but fully mobile, emptying my catheter myself and eating well.

Another good night although sleep was difficult with noises and general ward activity. On the Monday morning ward round I was discharged. My general recovery was deemed to be excellent with the only concern being the lack of any bowel movement despite a mild laxative.

Back home first week

On arriving home I slept for 3 hours. On waking I ate a meal and within a short time my bowels were healthy and active and have remained so to this day. We adjusted well to the home catheter routine including the night bag without any problems.

The rest of the week was a mixture of rest and exercise, although the latter was no more than a circuit around the ground floor of the house. Sometimes for a bit of excitement I would vary the route and take in the dining table. I was sleeping well at night in spite of a regular afternoon nap.

Back to hospital for catheter removal

The following Saturday, one week after the operation I went back into Stepping Hill overnight to have the catheter removed. I was admitted late afternoon and removal took place at midnight. This is to allow you to go back to sleep, wake with a full bladder and try to pass water. The removal itself was carried out with care and sensitivity and was no more than strange to uncomfortable. It was over in a couple of seconds and was not painful with no after-effects.

I did not sleep straight through the night and therefore was able to try out my new skill of peeing by about 3.00 am. Almost immediately I was able to urinate and experienced only a brief burning sensation which soon passed. After two further successful sessions at 6.00 am and 9.00 am, passing about 200-300 ml, the ward round doctor discharged me that morning.

Before leaving my stitches were removed.

Back home for good – convalescence

I was now back home one week after my operation on 13th January. The unknown area now was the possibility of urine leakage. Not knowing what to expect we had bought some sanitary pants with a fold to insert a sanitary absorbent pad. It appeared that I was in reasonable control of my bladder and

so we dispensed with the special pants and used instead press on absorbent pads in my y-fronts. From the start I have been dry at night and similarly all day with the exception of when I move quickly. Initially it was getting up from a chair and more recently sometimes when walking. The quantity is small however and manageable only requiring a single pad each day. I have had no trouble in passing urine and have had no pain.

During the week I had increased my level of activity around the house using the stairs two or three times in succession a few times a day. Due to poor weather I had not yet been outside. At the weekend we went out for lunch and I was able to walk a few hundred yards. Considering that I had felt fine in the house it came as surprise to me that walking outside caused some pain with a pull on the abdomen muscles. In addition after 10 minutes I felt quite exhausted. This was the first lesson learnt during my recuperation ie not rushing things.

It is now the third week in February and exactly 6 weeks have passed since the operation.

My recovery has continued well. Over the last few weeks I have walked each day and can now comfortably walk a couple of miles. Similarly steep hills do not present a problem either going up or down. The secret as I discovered is to listen to your body and work up to what is comfortable. Working through the pain barrier is not sensible.

I have not yet returned to the gym or swimming although I now feel ready to do so. I hope to be given the go ahead this week to start again.

Last week I started driving short distances without discomfort. Once given clearance to drive by your doctor remember to advise your insurance company.

My urine leakage has remained very low but constant. Before my operation I was very methodical with my pelvic floor exercises which I am sure helped in the early days of my recovery. However over the last few weeks and probably due to the fact that it has not been a major concern, I have been very poor in exercising. I now regret this and am taking steps to follow the very clear and consistent advice to do them regularly and continually.

Post operative consultation and results

I am now two days away from the six week follow-up appointment with my consultant surgeon at which I will receive the results of the biopsies carried out on the prostate and lymph nodes.

I have also returned to work this week for a few hours each day to break myself back in slowly. I feel fit and mentally ready to re-engage with the world although advice to take things slowly at first will not go unheeded.

I have now had my follow up clinic appointment with my Consultant on 21st February 2008. The news was excellent – my biopsies revealed that I had prostate cancer but no evidence of spread to the surrounding lymph nodes. As a result my Gleason Score had been recalculated from 3 + 4 ie 7 to 3 + 3 ie 6. In addition my PSA level had dropped to 0.1, the lowest possible recordable reading.

For the foreseeable future I will attend a 6 monthly clinic to monitor my condition. I was however declared to be 95-98% certain to be completely clear, it not being medically possible to guarantee 100%.

The two main areas for rehabilitation are to be my urinary control and re-establishing my erectile function.

Urinary control is essentially a function of constant pelvic floor exercises undertaken on my own. However as I have volunteered to be part of a MAPS survey [Men After Prostate Surgery], I have been referred to a physiotherapist at Stepping Hill for a series of exercises over a 12 month period to assess their effectiveness in reducing post operative problems. I have yet to start these.

I was however mistaken in my belief that if my level of urinary control appeared to be acceptable in the months after the operation, it would at worst stay at that level and at best improve even more. While this is apparently not an unreasonable assumption in the short and medium term, as I get older the lack of pelvic exercise now will ultimately decrease my long term level of control. This can only reinforce the advice to exercise regularly.

My erectile function has partially returned after a few weeks, although to a reduced level than before. The orgasm is dry but with no reduction in the level of sensation or pleasure. I was referred to my GP for a prescription of Cialis, a less commonly known drug than Viagra. After studying the possible side effects I decided not to take this and in its place was referred to a Vacuum Clinic at Stepping Hill. Essentially this is a pneumatic non-invasive method which I am about to start using in a few weeks. As with the urinary control, the Consultants advice was to treat it like a muscle and exercise accordingly since without such exercise, the blood supply to the penis will eventually reduce with consequent difficulty in achieving an erection. In a phrase that I will always remember with a smile, the advice was that “its future is in your hands, use it or lose it”.

Conclusion and reflections

The first point to be made is to recognise and applaud the sensitive and professional level of care and attention I have received throughout the whole

process from every member of the medical team. For this I am overwhelmingly grateful.

I would make the following observations on my experience.

- Take the necessary steps at an appropriate age to have your PSA level checked.
- Do not assume because you are fit and healthy that you are immortal and immune from such an illness.
- Once diagnosed familiarise yourself as much as possible with available literature to understand the nature of your illness - it will help you to ask the right questions and ultimately make the right decision.
- Discuss your illness with whoever you feel comfortable, but in my experience as widely as possible. Almost everybody appears to have an experience of a friend or relative who has had some prostate problems.
- Be as fit and healthy as possible when admitted to hospital.
- Be rigorous about regular and continuing pelvic floor exercises.
- Be patient in your recovery, which at first may seem slow, but with care and gradually increasing exercise will show improvement week on week.