

PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group (RPCSG)

Issue 38: July 2014

Website: www.rpcsg.org.uk

REPORT ON THE JULY MEETING

The July Open Meeting proved as popular as ever, with 58 people attending, including three visitors. Seven of our members gave talks to the group, and all of these presenters gave outstanding and interesting talks. Very many thanks to these people. A summary of their presentations follows:

Member1 had some internal pains during 2011, and then some blood in urine. A PSA test showed a level of 7, and shortly after this in February 2013 he had a biopsy that showed that he had aggressive prostate cancer. After a radical prostatectomy, his PSA was 0.029, and three months later was rising. He received differing advice on treatment - he was advised to have radiotherapy before hormone treatment, a differing advice said hormone treatment first. He took a private referral to Royal Marsden and a Choline PET scan, which revealed a recurrence in one lymph gland, which is an area that had not been treated previously. Surgery, or radiotherapy to all the lymph glands was advised, the latter to be followed by two years of hormone treatment. He chose to have IMRT (image guided radiotherapy) that targeted different areas, carried out in December 2013, and his PSA is now 0.004. He does not yet know whether this low value is due to the radiotherapy, or the hormone treatment, but his PSA will be measured again after about 12 months.

Member2 is aged 75 and began to suffer from some incontinence about two years ago and his PSA began to rise, and he had a radical prostatectomy in November 2012. His PSA is now negligible but he suffers from incontinence. He carried out the recommended pelvic floor exercises and estimates that he has done them more than

2000 times and spent 50 hours doing so! Bladder tests have found that his bladder has halved in size, and he was advised against having a sling operation. He now has very little urine control but is reasonably happy with the external sheath and collection bag system. His PSA is monitored every six months. This member would like to get in touch with anyone in a similar position, for a general discussion on experiences of treatments.

The wife of Member3 gave an account of the experience from her point of view, that she called 'The woman's journey'. To convey the sentiment of her talk, the following is the full text of her talk:

" Although prostate cancer is a man's disease, in its way it effects just as many women's lives; whether they're wives, mothers, daughters, sisters, aunts or partners.

So, as the wife of a man with prostate cancer, I thought I'd share the women's journey with you - with prior consent from my husband, of course.

I came to prostate cancer via the back door, or to be more precise, the bedroom door. Sexual problems make great jokes and can be really funny - if it's happening to someone else. I blamed my husband's job; stress; fatigue; the mattress; even the bedroom lighting. Then eventually, we blamed each other. By the time we got round to seeing a Consultant, six months of marital tiffs had passed.

A brain scan of the pituitary gland showed everything in my husband's head was normal - a surprise to both of us. A PSA test showed slightly raised levels, but "nothing to worry about and pretty normal for a 62 year old man" Testogel was prescribed, to boost testosterone.

The Testogel could be rubbed basically anywhere - but not where I thought was the

most 'obvious location.' The effect was disappointing - although my husband's hands did become very smooth and firm from applying it. Six months later, the only thing that had risen, so to speak, was my husband's PSA level. So a biopsy was taken. According to my husband, pain-wise this procedure's on par with child birth - but fortunately, you don't have to take anything home with you, or look after it for the next eighteen years.

Good News - the biopsy was clear. The Consultant prescribed - more Testogel and recommended a "romantic weekend away." To be honest, by this time, we were both thinking "Does it really have to be with each other?" But, undaunted, we gave it a less than successful go. Ever optimistic, I also booked a holiday abroad, in the hope that sea and sun might prove more effective, than Testogel and a dimmer switch.

Then, a change of Consultant and another higher PSA level, lead to an MRI scan and the Bad News. It was prostate cancer. My initial response of disbelief, shock and denial, soon gave way to fear, anger and a feeling of powerlessness. The second biopsy followed - together with my husband's painful realisation, why many women are quite happy, only ever to have just that one baby.

A PET CT scan confirmed that the cancer was close to the margins. I tried to get to grips with where my husband's prostate was and what it did, ever hopeful it was a bit of throw away anatomy - like his appendix. But I soon realised that although small and up to now inconspicuous, it was obviously a VIP in its own right.

The holiday had to be cancelled. On telephoning our Insurers, a rather amused young man told me our claim was void. I'd failed to read clause 96 of the small print, which stated any blood test had to be reported immediately, even if for erectile dysfunction and negative. Although I had considered the impact on our planned holiday romance, to be honest, I'd never actually thought about updating a complete stranger - on the intimacies of my personal life. An expensive lesson learned. Meanwhile, my husband was quickly whisked off to meet Robbie the Robot. His previous hospital admission, age 8, was for a broken arm playing leapfrog - so this was a huge step for mankind. The four hour operation, turned into 6 long hours due to complications - but 3 nights later, he was home. Minus his prostate and his dignity, but plus a catheter bag.

The dictionary definition is - "a tubular, flexible surgical instrument, inserted into a body cavity to withdraw fluid." My husband's definition was - "an absurd torture device shoved up a painfully unnatural place" - which gave a whole new meaning to the saying taking the proverbial p out of someone. My husband was unimpressed with the translucent, amoeba like, designer leg-bag, and even less impressed with my fumbling attempts to change it. Not all of us have that Florence Nightingale touch - and my efforts were compared to that of Harold Shipman. Then, catheter gone - I was faced with surfing the Internet for continence pads. This proved to be a bit of a minefield - or perhaps I should say waterfall? How was I supposed to know the difference between light, medium or heavy flow - having nothing previous to compare it with? Incontinence jokes are rife and can be hilarious - but not if it's happening to your husband. In desperation, I ordered a 'selection box' of different absorbency levels, shapes and sizes. I felt a bit like Goldilocks - some were too thick, some were too small, but eventually, I found one that was - 'just right.'

I soon realised that not only does prostate cancer change your life; it also changes your husband's wardrobe. I searched for 'fixation pants', that sounded like some sort of fetish underwear - believe me, they're not. I shopped for cargo pants with pockets to store the spare pads, and colours that concealed any accidents. My husband drew the line at a trendy man-bag - and my handbag soon became a portable storage unit.

Journeys and outings were time-limited and planned around where the next loo was. It was like a never ending game of Monopoly where you needed to stop at every station - and could never risk passing "Go." I learned that when walking holding hands, not to stop or change direction suddenly, as any jerky movement of mine, caused an adverse reaction from my husband - and the end of the outing.

I learned not to be upset by my husband's cross words and his mood swings. I learned when to be there for him and when to give him space. And then more space and then even more space.

Days started and ended with pelvic floor exercises and slow counting to 10. I often joined in by shouting "Coming ready or not" - but I'm not sure my husband always appreciates my sense of humour. Eighteen

months ago, he didn't even know he had a pelvic floor, but now he knows it so well - he could probably underlay and carpet it.

Then the Good News - the PSA reading post-prostatectomy was 0.03, so our Consultant suggested - another course of Testogel. By this stage, we both wondered "does he have shares in the company?" Now wary of the risks, we declined. We just wanted to be sure the cancer was gone.

Ever positive, my husband embarked on a self-management strategy to improve his fitness level. Attired in a pair of padded cycling shorts, he'd set off on his bike after lunch. But on the homeward journey as the schools were closing, his undercarriage and continence objected to the saddle - and he'd stop and slowly wheel the bike home. My vision - of a slightly overweight, profusely sweating and panting, middle aged man, clad in lycra, mincing past the school gates - rang alarm bells. I tactfully suggested he change his route, before he got arrested. Then, continence nearly mastered, we revisited the reason for our journey. A lengthy conversation with our GP followed, to convince him a prescription for a vacuum pump was a Health Need - and not just something on my husband's personal Wish List. A rep from iMedicare visited with his box of magic tricks, containing vacuum pumps and rings, in all shapes and sizes. Again, I felt like Goldilocks and spoilt for choice - but thankfully, my husband took control and decided to - 'go large.' To this day, I'm not sure if this was based purely on male pride. His DIY skills at home prove - he can't measure anything correctly. He's also never been able to successfully inflate a tyre on any bicycle or car. So, the pump is still a work in progress, but it's certainly given a whole new meaning to the term "rumpy pumpy."

Then, just as we thought our journey was ending, the PSA level rose and two months of daily radiotherapy followed. On a restricted diet excluding alcohol, caffeine, onions, spices, pulses and most green vegetables, my husband's mood plummeted. I'm no Nigella in the kitchen - and my husband claims most meals come with a Government Health warning. Thankfully, he survived both the radiotherapy - and my bland dinners - with neither of us ever being sure, which was the most lethal.

Then more Bad News - a follow up PSA test showed the radiotherapy had failed and the level had doubled. A second PET CT scan followed, which showed the cancer had spread to the ilium bone of the pelvis, so

more radiotherapy treatment and the commencement of hormone therapy - and our journey continues.

The Prostate Cancer UK helpline, has been a Godsend when I've needed to speak to an experienced and objective stranger. As well as when I just needed, to have a good cry. As a wife looking back, I blame myself for not knowing more, doing more - and probably at the very beginning, nagging more. I'm sure my husband won't agree with that last one. Would earlier detection have given a different outcome? Did the months of Testogel treatment accelerate the cancer? Who knows?

But what I do know is - there is a way through this long and winding journey. We've still got the same problem we started with, plus a host of others, we never anticipated.

But our ability to laugh about each life-changing stage - has been a survival tool. Laughter, apparently, has a therapeutic benefit that makes our hearts beat faster, our blood flow more briskly, and oxygen floods our cells. Laughter may not beat cancer, but it helps you to stay positive and keeps life in perspective. We've still got each other and the journey has made us stronger and closer as a couple. I'd like to thank my dear husband, for staying strong for both of us - when I know that inside, he's feeling anything but.

Reading Prostate Cancer Support Group has helped us every step of the way and made us feel we're not alone. So finally, and I'm sure for once my husband would agree with me - I'd like to thank all of you here tonight, as without this support, our journey would have been much, much, harder."

Member4 started to feel ill at Christmas 2011 with a loss of weight and appetite, and in January 2012 was found to have a PSA level of 822. Prostate cancer had spread to bones, chest, spine and pelvis. He started to have Zoladex injections every three months, and these have continued ever since, and has variously in addition had Casodex and Zometa (for bones). He had radiotherapy to a hip in April 2012, and a PSA of 6.6. In January 2013 the PSA was increasing, and Casodex was resumed. He had a TURP (prostate rebore) in April 2013 and six months later had a considerable improvement in passing water. PSA continued to rise and when it reached about 90 he then had six sessions (once per three weeks) of chemotherapy in Bracknell

starting in June 2013. After three sessions the PSA was still rising and when it was around 150 he was advised in August 2013 to have either further chemotherapy, or a new drug called Enzalutamide. He chose the latter and after six months of this treatment his PSA is 2.6. In spite of side effects of treatments, this member now intensively exercises, visiting a gym 4 or 5 times per week, and plays hockey. In Feb 2014 he was selected to represent England over 75 in the World Hockey Cup in The Hague, for which he won a silver medal.

Member5's Father died of Prostate cancer. Member5 had an increased frequency of visiting the toilet during the night. He had some tests that were clear, and he was told that he did not have prostate cancer, but that there was one little area that needed to be checked, which eventually was confirmed as prostate cancer. He had a bone scan and was then found to have a PSA of 7.6 and a moderately aggressive Gleason rating. After some confusing differing advice from different people, he decided to have a radical prostatectomy in January 2013. Whilst still in hospital after the surgery he had some palpitations in the legs, and some confusion, which soon cleared up. His surgery was nerve sparing but still suffers ED, but believes that the return of erectile function can take up to three years. Another member of the audience commented that he was similarly affected by total ED at eighteen months after prostatectomy, and on seeking further information on the extent of his nerve sparing, was unable to find any information but was told by a nurse that often the surgeons themselves do not know how successful nerve sparing has been, and was advised to "wait and see what happens".

Member 6 had a kidney function test five years ago, which found an enlarged prostate. He had then had further tests on the bladder and kidneys, bone scans and an MRI scan, and his PSA was 116. A biopsy found prostate cancer with a Gleason grade of 5+4. The bone scan was clear and the MRI scan showed that the cancer had spread to the pelvic lymph glands and hence there was no point in a prostatectomy. He was given hormone treatment, and it was suggested that he have TURP to relieve back pressure on the kidneys and a simultaneous orchidectomy, and these were carried out in January 2010. His PSA dropped to 0.43 but then had a slow rise, until the summer of 2013 when it started to rise more rapidly,

doubling in 3 months. A bone scan in Autumn 2013 was negative, and a CT scan showed no further spread of cancer than was originally diagnosed in the lymph nodes. In February 2014 his PSA was 56. Four months ago he was put a course of Abiraterone and Prednisone (an older steroid used to counteract the side effects of Abiraterone). After two months his PSA dropped to 29 where it has been stable for his most recent three readings, which is a good indication.

Member7 then presented his story, and so that you can read his full account, the text of his talk follows:

" I first came to Reading in 1962 as a History student at Reading University. Apart from three years living in West London I have lived in the area ever since. For the last eight years or so I have lived in Maidenhead so my prostate story relates to East Berkshire, not Reading.

Career-wise I was a teacher for over 40 years — at a Grammar School in Ealing and then three comprehensive schools in Berkshire. I retired in 2008.

Most of 2009 was spent diagnosing a heart problem, resulting in a by-pass operation in early 2010

It was my wife who drew my attention to the prostate and the need for a PSA test. Initially I found my doctor, back in 2008, reluctant to send me for a PSA but relented saying that it would be useful to have a starting point for future measures to be compared with. My reading in June 2008 was 2.8. We were happy with that! I had another PSA test as one of the blood tests after the by-pass operation and that was a similar score.

Not unnaturally my attention from 2010 on was more on my heart and it was not until October 2012 that I went to my surgery to ask for a PSA. I saw a locum who suggested I wait until the following March, when I was due to have my annual heart check, to do the PSA as well. I agreed.

In March 2013 I at last had the PSA test. The result came back at 6.8, somewhat higher than I had expected! Ten days later I went to see a urologist at St Marks, Maidenhead, who did a

rectal examination. He informed me that my prostate was enlarged but that he could not feel any evidence of cancer and he suggested that rather than go for a biopsy I should leave it and come back next year. I agreed. This is where my wife stepped in. She said we needed to get a second opinion. A friend of hers was secretary to an oncologist and through her we arranged for me to get a diagnosis privately. This involved going to a clinic in London for a specialist MRI scan at a clinic (cost £1085) in June. The result was to show that there was cancer, and a rectal examination by the doctor who was later my surgeon (£250), more thorough this time, confirmed the cancer.

There followed a bone scan at Harefield (confirmed it hadn't gone further) and a biopsy (confirmed the cancer). The surgeon I had seen privately also worked within the NHS and his speciality was Radical Prostatectomy. I saw him last August and the operation took place in Wexham Park hospital on October 8th 2013.

Some issues arising from my experience are:

1. The attitudes of GPs to the PSA test. There seems to be no common consensus — some feel it makes people worry unnecessarily and I have heard of at least one doctor who refused to agree to it for a patient. My first doctor (in 2008) was reluctant. My current doctor was supportive from the start.
2. The need to always get a second opinion. Had I followed the first specialist's advice I would have been due for my next rectal examination during March this year, 5 months after I was, as it happened, operated on. Who knows how far it may have spread by then?
3. Should MRI scans be made more available? Are they more reliable than a biopsy? It seems to me that they do need to be more widely used.

4. Paying for it — in the end I had to go private and pay for the diagnosis. Once that had been done the NHS stepped in and it was dealt with very well. A friend of mine, who had himself tested as a result of what happened to me, has been diagnosed as needing an operation but there seems to be a delay in it happening. It was suggested to him (by the hospital) that he could get the operation done more quickly if he was prepared to pay for it. (at least £15,000).
5. Side effects — incontinence and impotence. The incontinence issue especially took over my life for a number of months but both can be dealt with.

My PSA reading is still negligible and I am fit and able to lead a full life".

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All of the talks were very frank and personal, and my thanks go to those members who talked, and my sincere best wishes for future treatment.

Member2 would very much like to get into conversation with anyone in a similar position, to discuss treatments and outcomes. Anyone who would like to speak to this member can contact me at NewsEditorRPCSG@yahoo.com, or by telephone (as on the Contact Card) or via the web site, and I will help to arrange a discussion.

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The Chairman informed us of a PhD student who is carrying out a project concerning prostate cancer. The student would like to interview group members for the purpose of his research. The Chairman subsequently emailed some details of this student and his project, and members who would like to participate with this student are encouraged to make contact with the student in order to assist him with his work.

FUTURE MEETINGS

The 1st August meeting is intended to be a talk by one or more radiographers at the RBH on their work, and developments in that field. At the time of writing, we have been unable to confirm this event as the possible radiographer speakers are on holiday, so please check the web site nearer to the meeting for an update. There will be a meeting regardless.

The 5th September meeting will feature a talk by Diane Wootton, who is a physiotherapist working closely with RBH, and a specialist in incontinence and the pelvic floor.

Please visit the RPCSG web site shortly before each meeting, as there you will find the most up-to-date information on future meetings.

THE SUMMER SOCIAL

Our summer event, the Summer Social, will be held on Thursday 7th August at the Calcot Hotel, in the Kennet and Avon suite which has its own bar. It will be a two course buffet meal, for which we will meet in the bar at 19:30. The cost is £16 per person. This annual event is a very enjoyable occasion in a different and pleasant environment, and an opportunity to chat to other members of the group in a very pleasant environment. There will also be a quiz.

Please let us know if you would like to attend this function. You can contact the Chairman by email. The Calcot hotel needs to know the final number of people by the 22nd July 2014 so please ensure that you have booked your place by then.

Anyone needing more information about this event is welcome to contact me on the email address at the end of this newsletter, or the Chairman.

WEB SITE NEWS

Laurie Fineman has done a magnificent job over several months, in getting our web site set up and populated, and the committee is very grateful to him. The web site is a great

way of having information easily available to all, and an encouragement to anyone thinking of joining the group.

Unfortunately Laurie is soon moving away from the area, leaving us in need of a web site manager to take over the role of maintaining the web site. If anyone would like to take on this job the committee will be most grateful. It is not a difficult job and only needs a little ability with computers, and some artistic flair will help. It could even be a useful additional skill to acquire. Laurie will continue to manage the web site for up to 12 months, and he is very willing to spend some time with anyone taking on board this job, for tuition in the methods. Please contact the Chairman if you would like to become the RPCSG web site manager.

VASECTOMY LINK TO PCa

A report has recently been released that claims to have found a link between vasectomies and prostate cancer.

Research at Harvard Medical School and published in the Journal of Clinical Oncology, tracked a sample of 50,000 men aged between 40 and 75, over the period 1986 to 2010. They found that those who had had the vasectomy procedure had a 10 per cent greater chance of developing the disease. Furthermore, vasectomy cases have a sharp increase in the risk of contracting the most aggressive form of prostate cancer, although this type of the disease is still relatively rare.

The dangers appeared to be highest among men who had a vasectomy at a younger age, and the chance of developing the aggressive form of the disease increased among those who had a vasectomy before the age of 38.

Professor Malcolm Mason, Cancer Research UK's prostate cancer expert, said: "The extra risk of developing prostate cancer after having a vasectomy appears to be small but of the few that do go on to develop the disease, a higher number will develop an aggressive form.

About one in six men in Britain has a vasectomy. Experts said it was not clear why the procedure would affect cancer incidence

but it could relate to changes in the proteins in semen.

Dr Iain Frame, of Prostate Cancer UK said: "We need to be cautious about how the results are interpreted. Although there appears to be an increase in aggressive prostate cancer in men who have had a vasectomy, it translates as a relatively small increase in the number who develop aggressive prostate cancer."

You can read further about the report, at this web page:
<http://www.telegraph.co.uk/health/healthnews/10959787/Vasectomy-can-increase-risk-of-developing-lethal-prostate-cancer.html>

There is a very similar report in this web page:
<http://www.dailymail.co.uk/health/article-2687828/Men-opting-snip-greater-risk-prostate-cancer-Vasectomy-linked-lethal-form-disease-study-finds.html> which adds the following important paragraph:
"The authors emphasised that their study had only established a statistical link

between the operation and the disease – and they did not suggest that vasectomies were directly causing the cancer. They concluded, however, that urgent investigation was needed to establish if and why the surgical procedure might be increasing the numbers of those with cancer. "

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