

Notes of Prostate Cancer Support Group Meeting held at Dolphin Surgery on 9 March 2017

Peter, (Chair) welcomed everyone to the Members' Forum meeting, pointing out that it was particularly good to see a few wives/partners attending, whose support is invaluable to our members.

He outlined the format of the meeting where members will be given the opportunity to discuss their experiences of PC and treatment and any medical queries will be answered by a Specialist Urology Nurse, Lisa Holder who is based at Princess Royal and Brighton Hospital. Prior to the meeting, three men had already agreed to talk about their experiences.

Experience no.1

Roger commenced his story by explaining that he had always had private health insurance, but as a result of a visit to our support group meeting on 19 March 2015 at the invitation of a committee member, he opted to change to NHS service, which he believes made a huge difference to his general treatment.

Roger first became aware he had prostate 'issues' in 2011 when his first PSA test was 3.2. This rose steadily to 5.4 by Jan 2014.

Initially, because he had private health insurance he saw a consultant monthly at Gatwick Park, where urine tests were arranged, MRI scan, biopsy, advice on diet - to drink green tea, eat plenty of tomatoes, melon etc. He was advised the biopsy was clear but was told they were sending it to USA for more thorough tests. He was told he had a Gleason grade 3 + 3 and the blood test needed repeating in 3 months' time.

By Feb 2015 Roger's PSA had reached 5.7, which he was told was "not too bad", but he may need another biopsy. He was told they could operate to ease his urine flow problems and improve his PSA. However, he decided not to continue at Gatwick Park and to consider alternatives, as he felt the service there was greatly lacking in 'bedside manner' and relevant information.

In March 2015 he attended the Haywards Heath Prostate Cancer Support Group whose main speaker was Dr Fiona McKenna, Oncologist. Following a very friendly but informative discussion with her, Roger was advised to go for a second opinion on the NHS (which we are all entitled to) and, at the appropriate time, to ask for a referral to Eastbourne hospital which was close to Roger's holiday flat.

In January 2016 Roger's PSA had increased to 6.5 and his GP advised he should see a consultant (Roger had been taking Pomi T Tablets during this time). Things began to move very quickly from this point.

In February 2016 he saw the Urologist who arranged the following month for an MRI scan. Roger then had a second appointment to see the Urologist in May 2016 when he declined surgery and was advised that he should be suitable for 'seed implant'. An appointment was made for Roger to see the Oncologist in June where he was offered radiotherapy or, again, surgery, but the Oncologist did not recommend 'seed implantation'. Later that month Roger started Hormone tablets and Injections.

On 17 August 2016 the Oncologist advised he needed 20 radiotherapy sessions. He had a CT scan and was booked into Park Centre at Preston Park for his radiotherapy on 21 September 2016. The staff were very friendly, and made him feel as easy and comfortable as possible, accommodating pre-requirements at home re bowel/bladder. Roger found this very helpful, and he

could drive to the Centre in about 30 mins. The treatment itself took about 15 minutes, which included a CT scan to ensure precision of treatment.

On 6 October Roger had a review and was given medication to help ease urination (Tamsulosin). By 19 October the radiotherapy was completed and on 21 October he had a hormone injection which lasted 3 months. At Roger's next Review with his Consultant in November 2016 they discussed effects of the radiotherapy and hormone treatment (eg on bowel, bladder, weight gain, hot flushes) and was advised no further hormone treatment was required as PSA and testosterone were at required levels. He was advised the next review will be in 6 months' time prior to which he will have a further blood test to identify PSA (target is for a PSA to be not over 2). A further test on Testosterone will also be done.

In conclusion, Roger felt he could not fault the NHS service he received at all. This was delivered by extremely helpful, friendly staff who have been happy to talk, listen and advise, giving options where possible, even fitting in treatment around a holiday which was already booked.

Roger is so glad, and thankful, that he attended the support group meeting and took the advice of the Oncologist at the meeting to get a second opinion on the NHS.

Questions were then raised and discussed with Lisa, Urology Nurse:

re Zoladex Injection (hormone): Lisa confirmed that Zoladex Injection (which is used to lower testosterone can take different periods to work on different men. Sometimes it is a few months; others could take a couple of years, depending on 'variables' e.g. general fitness/health, type of cancer. Every man has different variables. A Stop-Start (intermittent) therapy is an option for some men for a set period, usually six months. Restarted when, and if, PSA rises again. This is usually done if the man is having a lot of side effects. Occasionally it will not resolve the situation.

re Effectiveness of Radiotherapy: This varies from patient to patient because of the variables previously mentioned. If after 5 years PSA remained stable then this would be very encouraging, but it would only be after 10 years that we could declare 'cancer free'.

Discussion took place on age limit for PC surgery. There was a basic age limit of 70 for the operation basically because as we get older we can get more frail and surgery may then not be the best option. However, if the man is fit and well with no other health concerns, and the surgeon is happy with the pre-surgery assessment, surgery may then be appropriate for a man a few years older than 70. Surgery is now carried out keyhole, laparoscopic by robot.

Lisa confirmed that, sadly, as yet computers in the health service/hospitals do not talk to each other. In the future it will happen, but not at the moment. Men have to rely on their GP for PSA results.

Experience no. 2

Dick was diagnosed at age 60 with advanced prostate cancer and his bone scan showed hot spots. He went to his GP as gradually he was urinating more frequently, and was asked for completion of a week's bladder diary, he had a digital rectal examination (DRE). Dick had an initial PSA of 485.

Dick compared the fact that we have bowel screening every 2 years yet no screening is done for PSA.

Again, he had received a very good service from the NHS. He was given Zoladex hormone therapy within 36 hours for 3 months before chemo, Docetaxel, could start - in line with Stampede trial recommendations. Dick was generally physically fit. The chemo was started very quickly, 6 phases every 3 weeks. This did affect his immune system, and after his 3rd dose, he developed a

very high temperature, was hospitalised as an emergency, and given strong antibiotics to stabilise him. While on the treatment Dick lost most of his hair and became rather weak but managed to continue with his part time job. He explained it has been hard at times as chemo attacks the healthy body as well as the cancer cells, but feels it was definitely worth it. Since the treatment he has had an extremely low PSA (currently 0.02). He was recommended a course of palliative radiotherapy where again, side effects (urgency in urinating and opening bowels) have eased.

Dick advised looking into complementary support and well being. He has attended the Penny Brohn Centre in Bristol, which is a well established 'Well Being Cancer Centre' with doctors on site, counsellors, dieticians to look at the person as a whole. He and his wife, Claudia, plan a third visit. He has found that keeping active and having an anti cancer diet has helped - and he thanked his wife for all her invaluable support on this. He has 1 glass of wine a day (max) more days than not, very little processed meats, eats plenty of broccoli, Pomi T tablets, tomatoes, green tea, brazil nuts etc. He feels diet is really important, and the healthy one he follows he finds easy.

Dick has to have Zoladex 12 weekly pellet injections for life.
Nothing was identified by genetic mapping.

If there are any other men with an advanced diagnosis who wish to communicate with Dick, he has given approval for them to email him, address as follows: Dickpagebrighton@aol.com

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Lisa confirmed that genetic mapping has a long way to go as it is so complex.

She also confirmed that as long as a man understands the pros and cons of the PSA test, it should be given. We all have a choice of whether to have a PSA test or not.

Speaker no. 3

Paul advised that the details of treatment for Prostate Cancer can vary from health authority to health authority. In 2011 after his (female) GP tried to put him off having a PSA test, he insisted, as a result of which he was a fast track referral with a 10.4 PSA. Paul's father had died in his 80s, and although he did have prostate cancer, this was not the cause of death.

Paul had researched treatment offered by his and a neighbouring health authority so he knew roughly what treatments were available. He had a 20 needle point biopsy which showed 12 positive needles out of the 20. He decided on robotic surgery and transferred from his health authority to Addenbrookes Cambridge University Hospital. He was told he was classified as having a Gleason of 3 plus 4, pT3a Margins negative. A 6 hour operation followed to remove the prostate. Paul advised that, interestingly, You Tube shows DaVinci Robotic operations which he had found useful. He was hospitalised for 36 hours and feels he probably left hospital a little too early, particularly as he had a 30 mile journey home. He had a catheter in for a couple of weeks. He declined the offer of immediate radiotherapy (Addenbrookes were carrying out a trial offering radiation immediately after surgery) because he was too tired to face it.

Paul saw the Erectile Dysfunction nurse six weeks after his treatment regarding methods of support. He chose a penile suppository (MUSE) and also Viagra because he seemed to have a very small amount of nerves left and hence Viagra had some effect.

He was a steady 0.02 PSA for six months and then it started to slowly rise over the next four years towards 0.1. Addenbrookes have a patient managed computerised system to monitor PSA called Trackmyspa which he used to record his readings - this automatically plotted a graph of his PSA and it was obvious to him that it was rising when it should not be - he was told this was because he was probably one of the 1 in 4 men who have a few Prostate Cells left in the prostate bed despite having the Prostate removed. When it reached 0.1 Addenbrookes called him back for Salvage Radiotherapy (20 doses of radiation), and the hardest part for him was drinking lots and lots of

water in order to ensure the bladder was full immediately prior to the actual RadioTherapy. He also had to give up eating pickled onions which to this day causes him anguish. Following this treatment, his PSA has remained below 0.02 for the past 9 months.

Achieving an erection has become slightly more difficult after the radiotherapy so with the encouragement of his ED Nurse, he tried Alprostadil injections into the penis, and found it did work very well and is far easier and less painful than you might imagine it to be !

See <http://www.nhs.uk/Conditions/Erectile-dysfunction/Pages/Treatment.aspx> for details.

Paul recommended purchasing a Radar key from Amazon c. £2.75 which will enable use of Disabled Toilets when urgent urination is needed. It is understood the keys are also available from local councils or PCUK. Re problem with incontinence, things can now be done at Eastbourne. He stressed men should not suffer in silence when things can be done to improve the situation.

He proudly said our role is to be missionaries and encourage other men, particularly those with PC in the family, to take the test.

Chairman's Summary of Meeting

Before Peter drew the meeting to a close he thanked our 3 wonderful speakers for giving their experiences with PC and treatment which had been both interesting and enlightening. He also thanked Lisa whose contribution on medical points had been invaluable. This had been the first 'Members' Open Meeting, and it was felt it had been very successful.

He gave the following information, which is also available on our website, for those who are interested:

Northumbria University would like as many people as possible to take part in a physical activity questionnaire on how people feel outcomes are being improved.

Tackle have a meeting at The Excel Centre in Docklands, London on 28 March -

There will be range of speakers on current topics. The Europa Uomo Board will also be present. The symposium will be chaired by Professor Frank Chinegwundoh MBE, from Tackle's Clinical Advisory Board. The current list of speakers include:

Dr Lina Carmona Echeverria, from UCH London, speaking about latest developments in prostate cancer diagnosis and treatment

Lawrence Drudge-Coates, a top Uro/Onco Clinical Nurse Specialist, visiting professor and honorary lecturer, speaking about the importance of bone health for prostate cancer patients

Rebecca Porta, CEO of Orchid Male Cancer, speaking about "Engaging Men in Health Messages", a new initiative in conjunction with Cancer Black Care, to raise awareness of prostate cancer in Black African and Caribbean men

Chris Booth, Emeritus Consultant Urologist and Chairman of CHAPS Men's Health charity, speaking about PSA testing and the current debate around prostate cancer screening.

Travel expenses will be reimbursed for all those attending. If you are interested in going to this event please email Simon Lanyon at simon.lanyon@tackleprostate.org . Places are limited.

NEXT MEETING

Our next meeting will be held on Thursday 20 July.