

Notes of Prostate Cancer Support Group Meeting Held on Thursday 25 July

Chair, Mike Streeter - Welcome and Introduction

Mike introduced himself welcoming members and asked if we had any new members. Graham identified himself, diagnosed in 2009. He gave brief outline of his journey to date. Mike said he hoped Graham would feel supported by us all and the information provided at our meetings.

It was explained that our speaker for the afternoon, Susan Drew from PCUK, sadly was not going to be able to get to us as her rail travel from Cambridge was not advised by Network Rail due to the very hot weather. She sent her apologies and hopes to be with us on another occasion to be arranged.

Update on Tackle Conference in June 2019

Mike recently attended the conference in Birmingham and gave an outline of what was discussed.

Discussions took place on the most effective way of diagnosing PC. It was explained that in America it is advised that every man should have the PSA test, but as of course there is no NHS, this could be seen as a money spinner. Prof. Monique Roobol-Bouts from Holland spoke about trying to identify who should be tested, age group, ethnic and family background etc, to see how focus can be on the people that need to be tested. It was acknowledged that there are false results both positive and negative, and there is no perfect PSA test at the moment. The big question is how we can use the resources of a health service most efficiently and at the same time identify those at risk and that need to be tested for prostate cancer.

A Urologist's Perspective on the PSA test. Jyoti Shah, Consultant Urological Surgeon, Burton Hospitals, said she became quite angry when men arrive to see her with a PSA of 500 mainly because their GP has refused to do the test, and by this time, there is little she can do for them. She said she is totally committed to PSA testing and had actually set up a testing stations at the local football ground and also elsewhere. She was committed to earlier detection.

It was felt that some GPs are deterred from referring men as the biopsy can apparently be dangerous, occasionally leaving a man with other problems. Of course, we now have MRI scanning before standard biopsy which allows more targeted biopsies and increases diagnosis of medium and high-risk prostate cancer. Apparently, one of the London hospitals is currently rolling out a new technique for biopsy where they go in through the front rather than the back inserting a small tube making it less dangerous. At first a full anaesthetic was needed but further development now means it can be done under local anaesthetic. This may transform the way in which GPs approach the implications of a positive PSA test.

A GP's perspective on prostate cancer screening - there isn't any! - Dr Ann William from Braintree spoke about risk management programme. Acknowledged test is free for any man over age of 50 who requests it and after careful consideration of the implications of such test. Before a decision is made she stressed patients should be given full information about the advantages and disadvantages of the test - bearing in mind GPs only have 10 mins with each patient and the request for a PSA may be raised at the end of a consultation, you can see the difficulty this presents for the GP! Statistics from a GP update showed of those men with a normal PSA, 1 in 6 will have cancer. The PSA test can miss prostate cancer; 1 in 50 men with fast growing prostate cancer have a normal PSA. . 66% of men who are offered a biopsy because of raised PSA will not have prostate cancer. Use of NHS resources is questioned. The test may lead to early detection, repeat tests can provide a benchmark. 1 in 3 who have a biopsy will have cancer. The question for the NHS is how to avoid unnecessary testing. Pointed out that 75 out of 100 men apparently get a false positive test.

Mike encouraged members to encourage their friends and family to be tested.

Burgess Hill & District Lions will be holding another PSA testing on 12 Oct in Burgess Hill, and our support group will be helping with logistics.

Brian's Journey with Prostate Cancer

Brian was diagnosed with prostate cancer age 69 on 8 October 2016 following a PSA test carried out at the Martletts arranged by B.Hill Lions. His wife had urged him to attend following receipt of a flier about the event which was posted through the door of their shop. He found the event well organised. A nurse did a simple blood test, which Brian believes saved his life. He was not experiencing symptoms other than getting up a lot to visit the toilet during the night he put down to old age creeping in. The whole procedure took no more than 20-30 mins. He was told he would get result by letter over 7-10 days.

This arrived and showed his PSA reading was 67 and further tests had to be done. Throughout Nov and Dec 2016 tests were carried out at Princess Royal Hospital, Haywards Heath with an MRI and ultrasound followed by a biopsy. Two Macmillan nurses came to the room to offer support and we were served refreshments. In Feb 2017 tests showed Gleason 4+5 with fast growing cancer cells, locally advanced, and he was given Zoladex treatment.

In June 2017 his PSA had fallen to 5.4 and his oncologist, Dr Robinson, outlined the treatment plan which was HDR brachytherapy followed by radiotherapy. HDR brachytherapy was given at Royal Sussex Hospital, Brighton which distributed radiation whilst minimising problems to surrounding tissue, organs, bladder/bowel. Brachytherapy is delivered through flexible plastic needles (21 in his case) inserted into the prostate between anus and testicle carried out in the operating theatre under general anaesthetic. A radioactive source is then remotely driven through each of the needles. Treatment can take up to 20-30 minutes. A scan was used by the Urologist to plan the treatment. Planning procedure took 2-3 hours. When the plan was approved he was taken for CT scans to check the needles were in the correct position. The 21 needles were connected to the HDR machine. There was a commentary and microphone system so that they could talk to me during the treatment. Always at least 1 nurse in attendance.

Brian said following the procedure when he awoke, the first thing he can remember is seeing seven young nurses at the foot of his bed smiling and saying "Good Morning Brian". He thought he was dreaming! Some of course were student nurses witnessing the procedure for the first time. He felt severe pain when the needles and catheter were being removed. He had to pass urine before going home, and then rest for 24 hours - no driving. Some discomfort was experienced at first when passing urine and with bowel movement, but this soon improved.

On 20 November 2017 he had radiotherapy (Tomotherapy) at Preston Park, 23 visits. Side effects were more wind than usual, needing to empty bowels more often, mucous from his back passage, tiredness and fatigue. His energy levels were affected. Hormone treatment ended in May 2019. He is still getting hot flushes, but getting up in the night isn't as frequent. February 2019 he had a PSA level of 0.58.

Brian explained his oncologist recommended brachytherapy, and he accepted his recommendation. It was explained that every treatment carries a risk.

Another member in the audience explained he had brachytherapy seed implant in Guildford 6 years ago and his experience was completely different from Brian's. He had no problems at all, he had no pain, and his PSA is undetectable. He took Zoladex for months before treatment was carried out. It was explained that each man's experience can be different.

A member had very recently started radiotherapy explaining he had to drink enormous quantities of water, having enemas etc., and said he had been advised that the side effects are likely to be urinary ones or bowel ones, plus lethargy. He wondered how much the huge quantities having to be drunk and all the enemas contributed to the side effects, or whether it was just the radiotherapy. Asked about any scientific tests having been done. PCUK have a booklet about side effects. Check out their website <https://prostatecanceruk.org>.

Member had brachytherapy seeds implanted 5 years ago. After about a year his PSA is creeping up again, and is now 16.

PCUK

With the planned speaker from PC UK not able to be with us, Terry gave a brief outline of the role of PCUK, explaining that Haywards Heath & District PC Support Group has become a partner support group of theirs and is evaluated by them. The last time a PCUK representative attended one of our meetings, his view was that our meetings were 'brilliant' and we should have more of them. Support Groups like ours have access to grants, advice, news, and insurance and also "The Tool Kit" information booklets on all aspects of the cancer journey.

PCUK was originally called the Prostate Cancer Charity and formed in the mid 1990s by an Oncologist at the Hammersmith Hospital, Jonathan Waxman, with a large donation from one of his patients, Lord Hanson.

PCUK gives support to individual patients and families and they have a Helpline where you can talk to a trained nurse or a patient who has gone through procedures and treatments. There is also an online patient fora and online information about diagnosis, treatment and living with cancer. Contact details are on our web-site.

The wider community benefits from research funding, lobbying and awareness.

It was pointed out that one of the reasons we limit our meetings to 3 a year is the difficulty in getting good speakers without duplication of topic. We also find that some speakers can only be available in the evenings which, we have found from experience, does not suit many of our members.

If any members have any suggestions on topics they would like to see covered by speakers, please email Jenny and let her know. jennyleauk@aol.com and we will do our best to cover this.

Date of Next Meeting

Thursday 28 November 2019

JL
29.7.19