

## **Notes of Prostate cancer support group meeting Held on Thursday 29 Nov 2018**

As the speaker sadly had a last minute accident and couldn't attend, it was decided to focus on a general discussion on PC with members' questions and experiences.

### **PSA Testing**

Brian, a relatively new committee member, talked about his journey to date with PC, He explained how he was diagnosed through the PSA testing at the Martlets. A leaflet was delivered into his wife's shop on testing day and he decided to attend even though his only symptoms were getting up in the night. He feels certain that had it not been for the test on that day, his PC (which was aggressive) would have been discovered at a stage which could have meant that his prognosis would have been far more serious. He had a Gleason score of 9. He has since had Bracytherapy and radiotherapy a year or so ago, and is currently on hormone therapy which isn't presenting too many problems.

Brian asked members if anyone else had been diagnosed with PC as a result of "accidental" testing (not specifically by a requested PSA test). 7 members hands were shown.

One member questioned why GPs do not suggest PSA testing. This we do not really know. Some GPs are happy to give the test; some are not. At the last meeting our Speaker, a local GP, said she would always be happy to give the test, if requested, but it should always be done in conjunction with a digital rectal examination.

It was noted that there sometimes seems to be a reluctance to use the services of the NHS unless it is felt really necessary, and the local PSA testing days in Burgess Hill arranged by Burgess Hill District Lions, in conjunction with PCaSO, may be proving the point. There were 444 men at the last testing day. The fact that an mpMRI can now be done which reduces the need for a biopsy is of course also very positive and reduces the negative impacts on those tested.

It was acknowledged that the publicity around Stephen Fry and Bill Turnbull's situations with PC has also had a very positive effect in publicising the importance of routine PSA testing, although routine testing is probably not going to happen in the near future. The importance of PSA testing to get a base line around age of 50 was stressed and this needs to be considered probably around the age of 45 for sons of those with PC.

### **Brachytherapy**

Questions were raised around brachytherapy. It was explained that brachytherapy is not suitable for all. It is not suitable unless the prostate cancer is localised.

Permanent seed brachytherapy, also known as low dose-rate brachytherapy, is a type of radiotherapy where tiny radioactive seeds are put into your prostate. Each radioactive seed is the size and shape of a grain of rice. The seeds stay in the prostate and give a steady dose of radiation over a few months. This is a curative treatment, as with radical prostatectomy, for localised prostate cancer.

There is another type of brachytherapy called temporary brachytherapy or high dose-rate (HDR) brachytherapy. A number of members have now been treated with this prior to external beam radiotherapy. More information at: <https://prostatecanceruk.org/prostate-information/treatments/high-dose-rate-brachytherapy>.

### **Exercise**

The importance of exercise for people with cancer was highlighted once more. Terry explained that Macmillan had funded a course to enable local exercise trainers to be accredited to provide supervised exercise for cancer patients. A member of the group is delighted to have become involved in the local case study included as part of this training, and has felt considerable benefit. We are moving forward on getting these supervised exercise programmes available locally. A representative from Macmillan is coming to our next committee meeting in January to discuss further developments on 'Living Well With and Beyond Cancer in mid Sussex' including improvements to the Macmillan facilities at the Princess Royal Hospital which may become more like the drop-in facilities available at the Royal Sussex and Queen Victoria (East Grinstead) hospitals. Our survey of members earlier in the year showed that very few of our members had travelled to the existing drop-in facilities.

Discussion took place on emotional problems throughout the journey on hormone treatment.

The Stampede Trial was referred to by one member, and for those who are not fully aware of basics of this trial, details are given below for information.

### **Stampede Trial**

(Systematic Therapy in Advancing or Metastatic Prostate Cancer Evaluation of Drug Efficacy) has been ongoing since 2005. STAMPEDE is a large clinical trial that is assessing new treatment approaches for people affected by high-risk prostate cancer. The trial has tested many different ways of treating prostate cancer and some results are now already known. Each new or alternative treatment is compared with the current standard approach. More than 10,000 people joined STAMPEDE.

The trial tested whether adding Docetaxel chemotherapy, Zoledronic acid, or Celecoxib, alone or in combination, was beneficial in controlling prostate cancer growth and improving life expectancy. The addition of Docetaxel was shown to benefit patients and this has led to a change in clinical practice.

In June 2017, the addition of Abiraterone for androgen-deprivation therapy has also been shown to be beneficial. In results presented in October 2018, the provision of radiotherapy to patients with metastatic prostate cancer, resulted in a substantial improvement in survival for some men. Recent findings show earlier and combined use of existing treatments can have a significant impact on advanced disease, but questions remain about its suitability for all men. Further results are expected in the next few years from other treatments tested in STAMPEDE. These include treatments currently used in different settings, including Abiraterone and Enzalutamide, both currently used when hormone treatment is no longer effective. Enzalutamide is a newer, life extending, drug again developed by Royal Marsden but cannot be used in conjunction with Abiraterone. Enzalutamide can have nasty side effects for some. It was very good to hear that one of our members taking Enzalutamide does not have nasty side effects.

It was acknowledged that, sadly, some men do suffer emotional problems throughout the journey on hormone treatment.

### **Braca 2 Gene**

It was explained that about 10% of men with PC will carry the Braca2 gene. A positive test result indicates that a person has inherited a known harmful mutation and, therefore, has an increased risk of developing certain cancers. However, a positive test result cannot tell whether or when an individual will actually develop cancer.

If a person learns that he (or she in the case of breast or ovarian cancer) has inherited a harmful *BRCA1* or *BRCA2* mutation, this will mean that each of his or her full siblings has a 50% chance of having inherited the mutation as well. Men would therefore need to make their families aware of this for the future of children and grandchildren.

### **Immunotherapy**

The future of course holds the prospect of treating cancer with Immunotherapy. Immunotherapy is a cancer treatment that helps your immune system fight cancer. Cancer cells are very good at disguising themselves. These new ways of treating cancer will expose cancer cells meaning the immune system will be able to attack them.

### **Conclusion of Meeting**

Mike thanked everyone in attendance and said he hoped the meeting had been a positive one.

The committee send their very best wishes to all members for the coming festive season with the hopes of a "Very Happy Christmas".

### **Date of Next Meeting**

Thursday 28 March 2019