

**Notes of Meeting held on July 16<sup>th</sup>, 2014**  
**Haywards Heath Prostate Cancer Support Group**  
**(Haywards Heath & Lindfield District)**

PETER introduced himself as the new Chairman. He thanked Ian for his years of service and the continued service of the committee. The tone was set with his funny jokes about “not finding his head” and “the second opinion” as well as his personal history with prostate cancer.

Many members paid their subs, with TERRY handling the paperwork. Some members will pay at next meeting. JENNY offered her warm welcome to all the attendees as they arrived.

ARTHUR brought the biscuits, which proved to be very popular.

The count was 27 people not including the committee, with one gentleman arriving at the end of the meeting.

**Speaker: Ann Payne**

ANN discussed the local services provided by Macmillan Info. & Support Centre in East Grinstead located at the Queen Victoria Hospital. The hours of operation are Mon-Fri., 9-5. There are many leaflets and other printed material available as well as internet research capabilities at this facility.

**Macmillan Cancer Information & Support Centre**  
**Queen Victoria Hospital, East Grinstead**  
**01342 414369**

Ann was joined by one of the 18 volunteers, Alan Greengrass, who assists in the operation of the centre.

They mentioned the services provided with an emphasis on the 3 types of homeopathic therapies currently available. These services include:

MASSAGE available on Tuesdays. REIKI available on Wednesdays and ACUPUTURE available on Thursdays.

All cancer patients are offered 4 free therapy sessions with further treatment available for a donation, suggested at £5 per session.

It was advised that Ann is contacted to reserve the session as early as possible, since the appointments fill up quickly. In addition, she can arrange easier PARKING by notifying her in advance that they are coming from the HH area.

The Macmillan motto was mentioned, “You are not alone, we are here for you”

Other centres are located in Brighton (smaller), Maidstone and Worthing.

Questions followed, with discussions on Zoladex changing personalities, menopause type symptoms, fatigue, etc.

Also mentioned was the lack of a support group in Brighton. However, many attendees discussed the good support they received while seeking treatment at Brighton.

A survey was taken to seek what the majority of attendees experienced with their stage of cancer. Most had RADIATION AND HORMONE THERAPY (HT). Some had surgery and Brachytherapy was mentioned as well.

A very social refreshment break followed.

**The second speaker CATHY SAMUEL, local PRH Macmillan Nurse.**

As usual, her talk was most welcomed and informative. Many members remarked how useful her information was and her invaluable presentation style.

Cathy job shares with Ann Jackson. Many of the members knew these two ladies and have utilised their services before.

She discussed the side effects of most of the HT medicines.

She explained why men are offered a particular treatment based on their individual PSA results and Cancer.

Cathy discussed the Robotic and HIFU treatments and how they have the same side effects as more traditional treatments.

She mentioned why NICE mainly offers Surgery, Brachytherapy and Radiology based on the long history of evidence available.

HIFU as a salvage treatment and high dose/boost brachytherapy are offered at Brighton.

The current radiation machines are older in Brighton with no new machines available in the near future. However, one is located at the Park centre.

PRH will remain the location for surgery, etc. but not radiation treatments.

HOT FLUSHES: it was suggested that Evening Primrose Oil, Sage Tea and Red Clover may offer some relief.

She stressed that HT was not a cure for PC, but acts as a delay mechanism. Many men take a BONE DENSITY test after using HT for 3 or more years. The average effectiveness is 3 years, but some PSAs rise after only 1 year - or as long as 10 years after initial treatment.

Once Zoladex or other HT treatment is no longer as effective it is NOT discontinued but steroids (affecting the kidneys), are added to continue the elimination of testosterone in the body.

Chemotherapy treatment lasts 30 weeks and is a personal choice on the quality of life offered as a result of this intensive treatment. The older you are the less likely it is offered.

Once again, it was stated that ALL men have different experiences with PC and the treatments are based on individual analysis.

Cathy did lighten the mood by discussing she is sometimes a “punching bag” who has a particular frustration with the Daily Mail PC articles.

After another Q&A session, the meeting was concluded.

Peter mentioned the tentative date of the next meeting, November 20<sup>th</sup>, 2014.

He also discussed how the committee is available for anyone who wants to contact us on a one to one basis.

MS

17.7.2014

**NB: Provisional date for November support group meeting may need to be changed. This will be confirmed to you asap.**