

**Notes of Haywards Heath Prostate Support Group Meeting
Held on Thursday 8 November 2012
at The Dolphin Medical Centre**

Introduction and Welcome

Jenny Stanger welcomed everyone to the second meeting of the Prostate Support Cancer Group, and gave relevant health and safety notification. She then introduced Ian Cooper, who had attended the July meeting, explaining that he had very kindly offered to Chair future meetings of the support group for which she thanked him.

Ian explained that he was diagnosed with prostate cancer 7 years ago and had undertaken hormone and radiotherapy. He is therefore in a position to clearly understand the support that is needed and should be offered to fellow prostate cancer sufferers. In this respect he feels strongly that, for the Support Group meetings to have guidance and a proper structure in the future, it would be advisable to form a small committee. Agreement on this was taken later.

Ian then welcomed Teresa Lynch, Specialist Nurse, Prostate Cancer UK, and suggested that if anyone wished to ask short questions during her presentation, that would be acceptable. Otherwise there would be a question and answer session afterwards.

Presentation - by Teresa Lynch, Prostate Cancer UK. Leading charity dealing with people affected by Prostate Cancer.

Prostate Cancer UK are the leading charity working with people affected by prostate cancer, funding Research (£7-8m annual commitment to new research over next 3 years); providing Information & Support to those affected by p.c., Working with Professionals to ensure best practice, and Campaigning to improve lives of men with p.c.

The Charity has a UK-wide telephone and email Helpline staffed by specialist nurses, and a one-to-one peer support programme provided by trained volunteers who have been personally affected by p.c.

The Charity is currently running a Fatigue Intervention Pilot Programme, the aim being to improve the quality of life for men living with and after p.c. This is a telephone-based service delivered by the Charity's Specialist Nurses which will be available early next year to all men experiencing fatigue. One attendee is currently taking part in this pilot programme.

**For Further Information on Charity: www.prostatecanceruk.org
Community Website <http://prostatecanceruk.org/we-can-help/online-community>
HELPLINE 0800 074 8383**

For the Publications Catalogue please Email: literature@prostate-cancer.org.uk or alternatively, ring 0800 074 8383.

Acknowledged strong parallel with Charity's funded clinical nurses and Macmillan nurses whose services are not only palliative.

Confirmed that prostate cancer can be an inherited disease. Statistics: 2.5 times greater risk of inheriting if father over 60 when he developed prostate cancer; 4 times greater risk if father under 60.

The effectiveness of different drugs and treatments incl. radiotherapy and Image Guided Radiotherapy (carried out at the Marsden Hospital), was discussed. Advice given on how regular, moderate, exercise could help to deal with fatigue (both physical and mental). One attendee felt that regular pelvic floor muscle exercise was very beneficial.

Acknowledged there is a need for more clinical nurse specialists/keyworkers to support prostate cancer sufferers. Charity working towards this.

Teresa confirmed their Helpline can direct a caller to a support group if needed. Stressed, again, the importance of men aged 50+ having annual PSA check.

Ian called to an end the Q & A session, thanked Theresa for her very thought-provoking presentation, and for dealing with the questions and comments from the group.

Raffle

A small raffle was held with prizes donated by Tesco, Sainsburys and personal friends. The money raised covered costs of this meeting. Future funding will be explored at the first committee meeting. Any ideas for fundraising would be gratefully received - please email Jenny Stanger on jennystanger@live.co.uk

Are you Willing to become a Mentor?

Ian requested that if anyone who has been affected by prostate cancer, or undergone any of the treatments, is willing to become a mentor on a one-to-one basis, they should please let Jenny Stanger know. (It was acknowledged that some of the treatments offered in the past are now no longer offered and are out of date.)

Committee - Setting Aims and Objectives

Ian took a vote on whether attendees wished the Support Group to continue, and this was agreed.

It was also agreed that a small committee should be formed with a Chair, Treasurer, Secretary and two ordinary members, although if anyone has an area of expertise that is relevant, such as a diplomatic nature, secretarial skills or accountancy, their help would be welcomed.

Support Group's Aims and Objectives:

- To provide support for those with prostate cancer, their families and friends
- To share experiences with others affected, especially those recently diagnosed
- To arrange talks from medical and counselling experts
- To form a casual social network of all those affected by prostate cancer in this area
- To raise funds for running the group and contributing to Prostate Cancer research

These objectives can be modified or fine tuned in the future as we learn more about what we are all doing.

It was confirmed that Ian Cooper would be the Chairman, Jenny Lea would be Secretary. Treasurer (to be confirmed), plus Jenny Stanger as committee member. Several attendees have offered their services as committee members, and Jenny Stanger will contact them shortly to arrange an initial meeting.

Ian read his personal 'Coping with Cancer Diagnosis'.

Ian stressed the need for everyone to be aware of problems outside the terms of reference for the group, with the aim of helping or supporting others wherever possible.

Steve Mackenzie from the Dolphin Patient Committee suggested contact be made with Jann Palmer or Elizabeth Carter of Mid Sussex Wellbeing whom he felt could be very helpful, particularly in connection with publicising the support group.

Open Evening at Royal Marsden

The Prostate Targeted Therapy Group is holding an Open Evening at The Royal Marsden on Thursday 13 December 5pm - 7.30pm, the main focus of the evening being to raise awareness of the clinical trials run by the group and to inform patients of the referral pathways from their current consultant/doctor. Jenny Stanger will be attending and will report on this at our next meeting. However, it is possible that, nearer the time, more tickets could become available for the meeting, and if you would like Jenny Stanger to apply for you please email her on jennystanger@live.co.uk.

Next Meeting

The next meeting will be on **5 March 2013, 7pm - 9pm.**

Our guest speaker will be Dr Bloomfield, Consultant in Clinical Oncology and Honorary Clinical Senior Lecturer, Sussex Cancer Centre. As he will be working during the day please note it is an evening meeting.

Before closing the meeting, Ian acknowledged, with gratitude, the input by Jenny and Phil Stanger in forming the Haywards Heath Prostate Cancer Support Group, and on behalf of everyone attending, offered a huge thank you.