

**Notes of Prostate Cancer Support Group Meeting  
(Haywards Heath & District)  
Held at Dolphin Surgery, 18 July 2013**

Prior to commencing the meeting Ian (Chair) stressed that all information shared at the meeting would, as usual, be strictly confidential and kept within the meeting.

## **1. Welcome and Update**

Ian welcomed everyone - new members and old - to the 4th meeting of our Prostate Cancer Support Group (PCSG) which has now been meeting for twelve months. He reminded us of the established purpose of the group, and felt that we have made good progress in all areas, as shown below:

- to provide support for those with prostate cancer(PC), their families and friends
- to share experiences with others affected - especially those recently diagnosed
- to arrange talks from medical, counselling experts and others where appropriate
- to increase awareness of PC and the need for early diagnosis
- to form a casual social network for those affected by PC in this area
- to raise funds for PC research

We received a grant from Macmillan to help cover costs of running the SG. More recently, Terry (committee) established a Web domain, our name being HaywardsHeathProstate.org.uk, which enables us to have our own email address. Website not yet set up. Currently, any emails are routed through Jenny Stanger.

A committee was formed to work on behalf of the group, although by the end of the year we are likely to lose three of the members: Jenny Stanger, Ian Cooper (Chair) and Jenny Lea (Sec). It is felt that as the systems and procedures are now already set up, the work involved for anyone wishing to take over the roles would not be time consuming, and contact could be maintained between new and old committee members where necessary. The Dolphin Surgery has confirmed that we could continue using this venue so long as there is a Dolphin patient on the committee or we are taken over by a PC charity.

In order for us to continue as we are at present, Ian asked that SG members give consideration to taking over a role on the committee. If we are unable to replace committee members, an alternative would be that the SG could be taken over by a charity to run it. PCaSO (Prostate Cancer Charity) have indicated their willingness to do this.

## **2. Joe Ambrosio's Presentation**

Joe (from PCaSO) introduced himself, and then unfolded his story as a prostate cancer sufferer who has been in remission now for over 3 years. He explained that, following a recurring urine infection, and antibiotics, then six months of tests followed by a biopsy, it was confirmed (against a general feeling that he was too young!) that he had prostate cancer at the age of 43. Many medical appointments followed, involving taped discussions and lots and lots of questions. He acknowledged the apprehension experienced prior to, and when attending, medical appointments, which can sometimes hamper what information is 'heard' or taken in. He felt that writing down your concerns prior to seeing the doctor, or even taking a dictaphone to the meeting, can really help. A pilot is currently running in Brighton whereby patients' concerns are established by nursing staff using an

iPad prior to the patient seeing the consultant. This information is then stored electronically and can then be accessed by the consultant before you see him to enable a clearer and more helpful discussion at the meeting. If you find you have a question that cannot be answered by the doctor or consultant, then make sure you ask 'Who can?'

When Joe was first diagnosed, he felt the first hurdle was actually coming to terms with the fact that he had cancer and to actually say the word. He then of course needed to find a way to give reassurance to those close to him that he would be ok. On bad days he found speaking to a Macmillan Nurse extremely helpful. He found the cyclist, Lance Armstrong's book about dealing with testicular cancer very informative and helpful, and explained that there appears to be a link between high PSA and cycling.

Joe also found attending a Support Group was very helpful, certainly for finding out about different treatments that other PC sufferers had received, and also those that were being carried out not only in this country but other countries.

Joe discussed, in general, side effects of PC treatment and explained that side effects, and the intensity of these, can differ from one person to another. The Prostate Cancer UK Helpline are very useful with their advice. He explained that pelvic floor exercises had proved extremely helpful to him personally in dealing with incontinence, and recommended these to the group.

Regarding erectile dysfunction which is another side effect that can be experienced, he explained there were several things available from the doctor to help, ie regular use of pump, injections, pills.

Joe has taken part in a pilot programme for Prostate Cancer UK which deals with the problem of Fatigue, and has made a video giving his own story. In the video he explains how very debilitating fatigue can be and that it has to be accepted it is a part of the recovery process. Strategies need to be put in place for coping with it. He outlined ways which helped him deal with fatigue, eg, by use of daily and weekly diaries which enabled him to take things very slowly, step by step. Joe explained it is a mental as well as physical problem, and something that can be difficult to come to terms with but the right strategy can help. Joe advised watching his video located on the Prostate CancerUK website -

Instructions for locating Joe's video are as follows:

**Once in ProstateCancerUK website, at top of Home page, Search for 'Get Back on Track' (the name given to the pilot Joe was involved in) and then click on link 'Get Back on Track', which will bring up Joe's video story.**

Joe emphasised the importance of talking to your wife/partner about the problems/side effects that can be experienced. This way they can be fully supportive and understand what the problems are. Joe found his partner was hugely supportive and encouraging.

Joe took Questions, and members of the group were given the opportunity to outline personal experiences.

Finally, Joe mentioned the current STAMPEDE trial which is looking at the effects of combined treatments on quality of life and finding out whether the new treatment combinations increase the time when the cancer is not growing and ultimately results in patients living longer.

### **3. Future of Support Group and involvement with PCaSO**

Roger Bacon, representative of PCaSO, talked about their organisation, outlined what they can provide as a charity and said they would be happy for Haywards Heath & District SG to come under their umbrella.

PCaSO have their own Website and Helpline, and produce their own leaflets plus a quarterly newsletter. Lifetime membership would be £12. They cover Sussex, Hampshire and Dorset with over 1,000 members and funds of £20k. They have a group in Eastbourne, Brighton, Rustington, and are hoping to start another in Pulborough area. HH & District SG would have access to all their leaflets and would be able to undertake collections as they would then come within a charity status. HH & District SG would retain their name, with any money going into the Sussex fund, and would need one member who would be the Group Leader to organise venue and speaker. PCaSO could advise on speakers. HH would effectively run their own group with the benefits of coming under PCaSO umbrella.

In the event that HH & District SG does not continue, the financial situation of the Group at that time would need to be addressed.

Steve Mackenzie of the Dolphin Patient Participation Group, who regularly attends the Support Group meetings, welcomed our acknowledgement of the need for confidentiality within the Group. He also felt that, although it is a difficult subject for some men, they should accept the need for practical help in dealing with side effects such as ED. He suggested that Citizens Advice Bureau can be a useful contact for other practical support and he advised the group to take a leaflet in case there were ways in which they could help. Steve also kindly offered his assistance in liaising with the Dolphin Surgery if problems were encountered in our retaining the meeting room for future meetings if we no longer met their criteria.

### **4. November 7th Meeting**

JennyS advised that we are aiming to have Prof. George Truscott talk to the group in November about the benefits of lycopene in the diet of PC sufferers, but in the event he cannot make the date, a suitable dietician will be booked.

### **5. Thanks and Reminder**

Receipts were issued for £5 subscriptions.

Ian thanked everyone for attending with a reminder -

**If anyone does want to offer his/her services on the committee and needs clarification about what is involved in the committee work, or indeed if you have any ideas about the future of Haywards Heath & District Support Group, will you please contact Jenny Stanger on 01444 456647.**