PHAROS

A beacon of hope in the darkness Newsletter of the Reading Prostate Cancer Support Group (RPCSG) Issue 49: June 2015

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THE JUNE MEETING

There were 55 members and wives at the June meeting, including two new members, one of them with his wife. A warm welcome to these new members, and I hope that they will find our group useful and will want to attend further group meetings.

The June meeting featured a talk by Mr. Paul Hadway. Paul was joined by Sammi Kaur-Gill who is one of the team of urology oncology Clinical Nurse Specialists at RBH. We are very grateful to her for her presence, and after the presentation, for remaining to help several people with some questions.

Paul joined the RBH just over a year ago, following the departure from Reading of Mr. Shah. The subject of Mr. Hadway's talk was 'Post Surgery Erectile Function Recovery Programme'.

Mr. Hadway's main remit was bladder cancer, and he is now a team member with the specialisation of prostate cancer treatments and prostatectomies with robotic machines. He has an interest in ED (erectile dysfunction) and he runs a clinic for this condition. He presented a set of slides on this subject.

He firstly described the physiology of erections. The process is complex but essentially is caused by the relaxation of muscles around cells in the penis that allows an increased rate of blood flow into the corpora cavernosa (the two erectile cylinders inside the penis) whilst veins contract, the result being an increase in the amount of blood in the penis thus causing an erection.

Nerves can be damaged during surgery, brachytherapy or radiotherapy. Recovery of erections can take 2 - 3 years.

A common cause of ED (erectile dysfunction) is furring of the arteries.

Tablets such as Viagra should ideally be taken before the operation, although this is not always possible.

Schedule 11 is a list of medical conditions for which the NHS will fund remedies post treatment, and prostate cancer is on that list. Typically four tablets per month can be prescribed. The provision of vacuum pumps is recommended but is at the discretion of GPs.

Tablets are available that help the erection process, once it has started. Hence they will probably not be as successful if the nerves involved in causing erections have been traumatised or removed. However the other remedies (see below) should work even though nerves are damaged or removed.

There are four main brands of tablets, with the commercial names of Viagra, Cialis, Levitra and Spedra. The taking of tablets is better done on an empty stomach, without alcohol, and with sufficient time for them to have effect. Mr Hadway recommended that post surgery, a patient should try each brand on at least 8 occasions, as a person may react differently to each tablet brand.

Mr. Hadway said that even with nerve sparing surgery, more than 70% of patients have erectile problems. Erections are very desirable in order to oxygenate the penis and to exercise its muscles, otherwise in the absence of erections, penile atrophy and fibrosis can occur. An erection recovery programme can begin about 4-6 weeks after

treatment. He summarised the treatments available and described each in turn:

PDE5 inhibitor tablets (Viagra, etc)
Vacuum pump
MUSE suppository
Vitaros cream
Injections into the penis (Caverject)
Prosthesis (either malleable or inflatable)

Mr. Hadway was thanked with a gift, in appreciation for his most informative talk.

CARERS SUPPORT GROUP

At our group meeting of June 2014 there was a presentation by guest speakers from Macmillan, on their Well Being programme. One of those speakers was Jane Woodhull whose role has now been taken on by a lady named Kate Rawlings, and Kate has also started a Carers Support group as part of the programme. This group meets on the first Wednesday of each month from 1.00pm to 3.00pm at Earley Crescent Resource Centre, Warbler Drive, Reading, RG6 4HB. Phone no. 0118 9210555. This is adjacent to Lodden Valley Police station.

Spouses, partners, family members, carers or anyone involved with caring for cancer patients are all welcome to attend this Support Group.

Refreshments will be served and parking is free. Please come along to this group if you are interested, or telephone the number above for any details.

DATES FOR YOUR DIARY

THE JULY GROUP MEETING

This will be on the 3rd July. The meeting will be 'Open Forum' and the topic of the meeting will be travel insurance. Many of us have had issues of some sort with travel insurance, such as the cover provided, the cost, and even the availability of insurance at all. At the Open Forum some committee members will relate their experiences of travel insurance, and then the discussion will be opened to the audience. So before the meeting, please look into your travel insurance both past and present, and we will

be most interested to hear of your experiences, from which we all may benefit.

SUMMER SOCIAL

The Summer Social will be in the evening of 15th July 2015, from 19:00, at the Calcot Hotel, the same place as last year, which was a very suitable and popular venue. The meal will be a two course buffet, and during the evening there will be a picture quiz, and a raffle. The buffet will consist of cold meats and salads, a hot dish with vegetables, and a dessert. A vegetarian option will be available.

Anyone wanting to attend can pay the cost of £16 per head to Keith Hunt, during the July meeting. Otherwise, you can post a cheque to Keith at:

Neframa Sandhurst Road Wokingham RG40 3JQ

Cheques should be made payable to 'Reading PCSG'. Please book your places as soon as possible, so that we can get an idea of the number of people interested. You can easily do this by an email to Keith on: keith hunt@btinternet.com

RACE FOR LIFE

This will take place on the 26th July 2015 in the Newbury showground, and we will run a prostate cancer awareness stand there. It is a fund raising event on behalf of Cancer Research UK so is for a very worthwhile cause. It is mainly a run of 5km, although walking and dawdling are adequate! The theme of the event is 'Boys Beating Cancer' and the race participants are male only. Of course all members' families are welcome to come and support them. You can find more detail of the event in the following two web pages. Please come along for a fun day out in aid of a good cause.

http://www.boysbeatingcancer.org/about

http://www.boysbeatingcancer.org/event-information

At our awareness stand there will be a game for the public to play. It is a speed gun that measures and displays the speed of a

football, and members of the public are invited to kick the ball and try for a high score. The game costs an amount for three tries (possibly at £1) and so should raise some money for our group. This game has been used at other events and has been very popular, so we hope for a good deal of interest in our nearby awareness stand.

Our committee member Derek Jackson has kindly taken on the task or organising the awareness stand, and would greatly appreciate any volunteers to be present at the stand. He will arrange for the volunteers on a shift basis of about a couple of hours each, so volunteers will be able to spend some of their time enjoying the other attractions at the event.

The first race is at 10:30 and the last is at 12:30, and the public will probably be around until about 14:00. We intend to run the awareness stand from 9:30 until about 13:30 and anyone who is willing to help out will be very much appreciated. The task is not difficult, it is just to engage with anyone who has an interest in our stand, by giving out leaflets and answering any questions that they may have. If you are able to offer yourself to do a session on the stand, or you would like some more information about it, please contact Derek by email: derekjackson761@gmail.com

THE AUGUST GROUP MEETING

On 7th August Jayne Doyle will give us a talk. She is a complementary therapist with a private practice, and will talk about the role of complementary therapies in both the diagnosis and treatment of cancers including prostate.

THE SEPTEMBER GROUP MEETING

On the 4th September there will be a talk by Nikki Hayward. Nikki is a Senior Nurse with Cancer Research UK, in the Research & Engagement unit. She will talk about advances in research, Clinical Trials, and the awareness and prevention of cancer.

PAST EVENTS

The PCSF (Prostate Cancer Support Federation, usually known as 'Tackle') held their annual conference and AGM on the 15th July 2015. One of our committee members attended, and found that it was a very useful and informative event. The slides that the two speakers used will be on the PCSF website in a few weeks.

AND FINALLY...

As our next meeting will be about travel insurance, you can see below a list of places for which you will not need insurance! Thanks to the member who sent this humorous article:

I have been in many places, but I've never been in Cahoots. Apparently, you can't go alone. You have to be in Cahoots with someone. I've also never been in Cognito. I hear no one recognizes you there.

I have, however, been in Sane. They don't have an airport; you have to be driven there. I have made several trips there, thanks to my friends, family and work. I live close so it's a short drive.

I would like to go to Conclusions, but you have to jump, and I'm not too much on physical activity anymore.

I have also been in Doubt. That is a sad place to go, and I try not to visit there too often. I've been in Flexible, but only when it was very important to stand firm.

Sometimes I'm in Capable, and I go there more often as I'm getting older.

One of my favourite places to be is in Suspense! It really gets the adrenalin flowing and pumps up the old heart! At my age I need all the stimuli I can get!

And, sometimes I think I am in Vincible but life shows me I am not.

People keep telling me I'm in Denial but I'm positive I've never been there before! I have been in Deepshit many times; the older I get, the easier it is to get there. I actually kind of enjoy it there.

So far, I haven't been in Continent; but my travel agent says I'll be going soon.

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