

PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group (RPCSG)

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THE FEBRUARY MEETING

There was a good attendance of 51 people for the February meeting, including two new members and their wives.

There was a very interesting talk by Janet Forgenie. Janet is Clinical Nurse Specialist (CNS) at the Royal Berks Hospital, in the Uro-oncology team. Janet started by defining a CNS, and the role. A CNS is an advanced practice nurse, and the goals are to provide continuing improvement in outcomes and nursing care. It is a unique and valuable role providing advanced medical knowledge and support for patients.

The main aim of the CNS team is to improve patient outcomes and nursing care, and there are benefits to both the NHS and patients.

The benefits to the NHS of the CNS are that the CNSs are very cost effective - they are guidance based, members of the multi-disciplinary teams, helping to reduce referral times and length of stays in hospitals. They participate in hospital admissions and attend in clinics, e.g. during prostate biopsies and follow up consultations, and help to reduce post-operative complications.

They operate a 62 day Pathway, which is the target time following GP referral, for a patient to be consulted, diagnosed and treated. CNSs visit patients fairly soon after surgery.

The benefit to patients from the CNS team are several - the team is patient centred and a point of contact for patients. The team members keep themselves up to date with new developments, and they provide easy access to consultants clinics and can arrange appointments. The team is knowledgeable, transparent and honest, and provide support and continuity.

The team at RBH consists of:

Janet Forgenie
Tessa Martin
Sammi Kaur-Gill
Donna Woodward
Louise Hultquist (sponsored by Macmillan)

The workload in the unit consists of cancers of bladder, prostate, kidneys, testicles and penis. There are nurse-led clinics, aiming for education, service development and Pathway management.

There are nurse-led clinics for:

- Abiraterone (soon to include Enzalutamide) which started in September 2014
- New oral chemotherapy clinic for kidney cancer, soon to be established
- Berkshire bladder cancer service, started in October 2014
- On-going service development

Mr. Paul Hadway (Consultant Surgeon at RBH) is setting up an erectile dysfunction clinic.

Finally Janet said that anyone can telephone the CNS team, even when in remission. Privately treated patients can also make contact, and no-one is considered to be discharged. Janet explained that the telephone is an answering machine service, because the nurses have to access the patient records before they can reply. In an urgent situation, a patient can say so on the message, and the team will respond as soon as possible. A member of the audience expressed great thanks to the nursing team for their help, with which we all agree.

Janet was thanked by the Chairman for her very interesting talk and presentation, which included photographs of her children and dog!

MORE ON TRAVEL INSURANCE

I am very grateful to a member who sent to me some information about his experience with travel insurance. The member booked a cruise and took travel insurance via the holiday operator. He was then diagnosed with prostate cancer, and on informing the insurance company, they cancelled the policy and returned the premium, with about two weeks before the cruise was due to start. He contacted several travel insurance companies, only to be declined by them all. He already had a medical insurance policy with AXA, and enquired with them for travel insurance and obtained a quotation. He then explained his diagnosis and AXA was quite happy to offer the policy, provided only that he considered himself fit to travel. The only stipulation, which is common in travel insurance policies, was that the illness was not terminal within 12 months. The member's policy was for Comprehensive Worldwide cover which allows 183 days per year of overseas travel per year and any one trip up to 65 days. They offer a more extensive policy called Luxury Worldwide cover.

If anyone would like to enquire with this company, the telephone contact is:
AXA PPP Healthcare 0800 587 0954

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In the September 2013 issue of the newsletter, I reported how following diagnosis and prostatectomy, my travel insurance increased from £70 to £108, for two people multi-trip to Europe, and including cover for my cancer condition. Since then I was diagnosed with a urethral stricture that required an operation in January 2014, and as this caused incontinence I had an operation to fit a sling in August 2014. I declared all this to the company, and my number of visits to a doctor in the last 12 months then fell into the category of '5 or more'. On renewal in September 2014, the company (Employee Advantage) excluded cover for anything concerning my prostate cancer and its side effects, and the premium returned to £70.

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On the subject of travel, there was an amusing report of a British man returning

from a holiday in Spain. On preparing to leave the hotel, he found that his passport had been stolen from the hotel safe, but he and his family turned up at the airport anyway, he expecting to have to visit the consulate for replacement documentation and then book another flight. The desk staff said that an alternative identification would be considered, so he telephoned his daughter and she faxed his bus pass to the check-in desk, and he was allowed to fly home. British immigration was not pleased. You can read about this story at the following link. My confidence in hotel safes has now been shaken:

<http://www.dailymail.co.uk/news/article-2948861/Retired-teacher-65-used-photocopy-BUS-PASS-board-Ryanair-flight-Spain-UK-passport-stolen.html>

EVENTS

On 6th March we will be holding an awareness event in the Broad St. Mall in Reading. This involves shifts of two hours, each with three or four of our members. We will give information about prostate cancer to passers-by, and talking to and giving information to anyone who approaches our stand. If anyone would like to participate in this event, please contact the Chairman.

On the 11th March the Reading Lions will be holding one of their regular PSA screening events at the Circle hospital in Reading from 16:30 to 21:30. Any man wanting to have his PSA checked can just turn up to give a blood sample, and he will be informed of the outcome by post. Anyone with a PSA level that is outside the normal range, will be advised to seek a hospital consultation. These events have screened more than 1,000 men in two years, of which 52 men were advised of abnormal or serious outcomes. If you have any friends or relatives who could benefit from this test, especially in the cases of a family history or having any symptoms, please let them know about this event.

On 20th March there will be a Health Fair event at Henley-on-Thames Town Hall. We will be having an awareness stand at this event, so if you live conveniently close to Henley and can help at this event, please contact Peter Reader by email on henleyreaders@btinternet.com

NEXT MEETINGS

The meeting on the 6th March will feature the AGM, which will not be very long, and following the AGM we will be showing some internet videos that give some stories of men and how they managed the side effects of their prostate cancer treatments.

The meeting in April will for once, not be on the first Friday of the month as this happens to be Good Friday. Instead the meeting will be on Friday 10th April, at which the guest speaker will be Charlotte Robinson of the Radiography unit at RBH, and she will tell us about the work that is carried out in that unit.

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