

PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group (RPCSG)

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REPORT ON THE APRIL MEETING

The April meeting was quite well attended by 38 people, including four new members.

The April meeting featured a talk by Carol Munt. She is a qualified nurse, and the Chair of the South Reading Patient Voice, which is an organisation aiming to improve the support for patients, and this includes the carers for the patients. The RBH encourages relatives of patients to join the Group. The Group has become involved in a wide range of items for attention, from small things such as the noise and lighting levels, and quiet closing bin lids, to the very large such as car parking and access. The Group aims to make a difference for not only patients, but their carers as well. It is recognised that most patients need to have someone to look after them during their treatment, and caring is recognised as a difficult role and often involves carers incurring costs. The Group aims to ensure that carers are treated with respect, are provided with adequate nourishment and accommodation, and are involved in consultations and care plans.

The Group encourages the formation of GP Patient Practice groups, which can look at subjects such as the appointment system, and facilities such as toilets, bicycle facilities, leaflets, and noise levels.

Carol said that the point at which a person becomes a carer is open to discussion. A person accompanying a patient for a treatment involving an operation and one night stay in hospital would not make them a carer, but for a course of radiotherapy for example, it would be a carer situation.

Carol then described the Carer Passport system. This enables a carer to obtain a

passport which acknowledges the carers right to the facilities already mentioned, and also provides free parking. The Passport can be obtained from the ward in which treatment is provided, and is valid for the duration of the treatment.

The subject of car parking raised many comments from the audience, who recognise that parking at RBH is far from ideal, and very difficult when the parks are full. Carol said that priorities are the ability to get patients to the hospital, and for them to be collected easily from the discharge bay.

Carol was presented with a bouquet of flowers as a token of thanks for her effort in giving the talk.

FUTURE MEETINGS

The next meeting will be on Friday 2nd May, and will feature a talk by consultant Mr. Philip Charlesworth, who has treated many of our members at RBH.

The June meeting will see a talk given by Jane Woodhull of Macmillan Cancer Support.

The July meeting will be another of the always popular 'Open Meeting' where some members will give their accounts of their experiences.

Please visit the RPCSG web site shortly before each meeting, as there you will find the most up-to-date information on future meetings.

PROTON BEAM THERAPY

There has been a report in the media of a revolutionary new treatment that is not yet available on the NHS. It is called proton beam therapy and is similar in principle to external radiotherapy, but uses proton beams instead of x-rays. The advantage of protons is that they are not absorbed by the tissue that they pass through, so they kill the cancer cells whilst not affecting the healthy tissue that they pass through.

The success rates are similar to conventional treatments, and there should be lesser side effects, although this is of course not guaranteed.

As the treatment is not available from the NHS, many British men have paid for and received treatment at a major European centre - the Prague Proton Therapy Centre. Treatment costs about £16,000 for cancers in the early stage, and almost double that figure for advanced stage cancer.

There is no proton machine in the UK, and two things are possibly contributing to this. The cost of each machine is £125 million, and there are the inevitable sceptics - some doctors claim that there is "a lack of robust clinical evidence to prove its worth conclusively over conventional radiotherapy".

You can read the report on this treatment on the following web page. The report uses the illustration of Joe Tuftnell, who used the Prague centre for treatment rather than follow the advice of his UK doctors for Active Surveillance.

<http://www.dailymail.co.uk/health/article-2566904/Prostate-cancer-breakthrough-NHS-wont-offer-It-spare-men-like-Joe-effects-treatment-So-available-abroad.html>

This article mentions Peter Keyssel who spent £17,000 on treatment in Prague, and has put in a claim for the NHS to refund this sum to him. It will be most interesting to know the outcome of this claim, and I will watch for a result of this case.

The Government announced in August 2013 that it will spend £250 million to provide two proton therapy centres, at the Christie

Hospital in Manchester, and at University College Hospital in London.

However, it seems that prostate cancer sufferers will miss out yet again, as the Government has said that the treatment will not be available, at least initially, for prostate cancer patients, it will instead be used for childhood cancers and rare adult cancers such as those hard-to-reach ones at the base of the skull or spine. This is yet another prostate scandal, as the Proton Therapy Centre claims that the incidence of impotence is about 30 per cent for people who have proton beam therapy, compared with about 60 per cent for conventional treatment. However a British firm is developing a newer cheaper proton therapy machine which will cost only £26 million per machine, with an intention to have proton beam therapy in ten UK locations within five years.

The 61 year old television celebrity cook Ken Hom was diagnosed with aggressive prostate cancer in March 2010 following a routine annual check-up in Thailand. He underwent the Proton Beam Therapy in Japan, having 37 sessions in two months. His cancer was most unexpected as he swims daily, has a healthy diet and drinks green tea, which is supposedly a prostate cancer deterrent. He now has a PSA check every three months.

You can read more about Ken's story on this web page:

<http://prostatecanceruk.org/news/2010/10/ken-hom-speaks-publicly-of-prostate-cancer-for-the-first-time>

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