PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group (RPCSG)

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THE NOVEMBER MEETING

The October meeting was very well attended by 66 members. There was firstly a discussion on patient information leaflets regarding brachytherapy, presented by Kim Day. Then a welcome return visit by Dr. Helen O'Donnell, a consultant oncologist at the Royal Berkshire Hospital. Finally we were visited by Richard Green, the Ph.D. student who has interviewed several of our members.

Kim Day firstly described a new patient information leaflet that is being prepared to give to each newly diagnosed patient, to inform them of the brachytherapy process. Kim is looking for some feedback from members on the content of this leaflet. The production of this leaflet will enable patients to carefully consider the information in their own time and help them to make up their mind on a treatment option.

Dr. Helen O'Donnell then spoke to the meeting by asking for questions from the audience rather than give a presentation. This proved to be an extremely useful approach with many questions being asked. The following paragraphs are a summary of Helen's replies to questions:

Treatments for prostate cancer include Radiotherapy, hormone therapy, brachytherapy, and more recently new treatments for more advanced prostate cancer have emerged such as chemotherapy and new drugs.

Recurrence after primary treatment is a grey area. Following surgery, radiotherapy can be used. After external beam radiotherapy, hormone therapy is usual. After brachytherapy, salvage prostatectomy can be carried out but any surgery after radiotherapy carries the risk of side effects including incontinence.

A member asked what treatment could follow his case - he was diagnosed in 2004, treated with radiotherapy, cancer returned in 2010 and he then had surgery. Helen advised that hormone treatment could be applied, and added that chemotherapy originally was the usual treatment after failure of hormones, but now there are the new drugs of abiraterone and enzalutamide which are usually introduced after chemotherapy. However abiraterone is now licensed pre-chemotherapy and is available as such through the Cancer Drugs Fund. Enzalutamide is licensed post-chemotherapy, but based on evidence to date it seems likely that both of these drugs will eventually be available pre-chemotherapy. However after the use of one of these drugs, further treatment by the other will result in a lower response.

Functional MRI is very good for evaluating the grade of cancer in the prostate. We still use CT and bone scans, and in the near future we will be able to use choline PET scanning, which is very good at detecting cancer outside the prostate.

PSA is a very sensitive indicator of prostate cancer following a prostatectomy, and would be main tool for ongoing monitoring, rather than scans.

Testosterone levels in the body will eventually recover after hormone treatment finishes. After hormone treatment over 3 years, testosterone level can take 1½ - 2 years to recover.

A member completed radiotherapy and hormone treatment 2½ years ago, but still has hot flushes. Helen suggested a testosterone level check at his next blood

test, as flushes suggest that testosterone is still low.

About 4 years ago the thinking was that brachytherapy is most suitable for low risk cancer, but it has recently been found to be suitable for intermediate risk cancer as well.

A member who is having hormone treatment following a recurrence a few years after brachytherapy, enquired as to how long the hormone treatment might continue for. Helen said that no definite time can be stated, only the average which is about 24 months, but that some patients have been on hormone treatment for about 5 years. If a patient on hormone treatment has a rising PSA level and low testosterone, then the hormone treatment would continue but additional hormone therapies would be considered. The length of time that this could continue for is uncertain, and each case would be considered individually. A comment was made that a patient was doing well after 12 years on hormone treatment.

Orchiectomy is still used in some cases but is now rare, and at one time was the only treatment before the testosterone reducing drugs came along. Orchiectomy rapidly lowers the testosterone level, removes the need for regular application of drugs, and is useful for very advanced cancer, or when it has spread to the bones. Hormone treatment is not usually needed after orchiectomy, unless some adverse issue arises.

After surgery and/or radiotherapy, if the PSA is low and there are no symptoms, no further action is usually taken unless the PSA begins to rise. Rate of rise is equally as important as the absolute figure of PSA value.

After hormone or radiotherapy treatments, Gleason scoring cannot be done as the nature of the cells has been changed. However biopsies can tell whether there is a presence of cancer cells.

Some testosterone is produced by adrenal glands that are near to the kidneys, and this source is fixed by hormone treatment in tablet form. Consultants have varying preferences for the dosage level of treatment, which can vary between 50 and 150 dependent upon whether injections alone are given, or hormone tablets as well as injections. The exact dose is not too critical as there is a saturation point above which further increases in dosage will not have a proportional increase in effectiveness.

A member commented on a lack of interest in prostate cancer by GPs, and Helen said that there is an ongoing debate about routine screening for prostate cancer. PSA screening does not fulfil the requirements for full screening. Some opinions are that PSA screening may do more harm than good, in the cases of false results, unnecessary biopsies, some of which have proved fatal in a few instances, and side effects of biopsies.

Any man can request a PSA test if he is in the appropriate age range or has a family history of the disease

If a stable PSA level starts to rise, it is the rate of rise (time to double) that usually indicates the severity of the increase. Rectal examinations (and other things) can temporarily raise the PSA level so should be avoided before a test.

The quantity of radiotherapy sessions is adjusted for each individual patient and the knowledge of appropriate levels is increasing. A clinical trial used a starting level of 64 Gy (Gray units) and increased the dose over a number of sessions (37 was mentioned) up to a level of around 74 Gy. Investigations are continuing over the optimal increase in dosage, e.g. whether to increase by 1 or 2 Gy per session. These trials suggested that higher doses are safe, and so it is now possible to offer treatment of 4 weeks duration to some patients. The dose has to compromise between effective treatment and the possibility of damage to surrounding tissue, which may cause bleeding.

We work in conjunction with other countries, mostly European, to collaborate on trials and so benefit from the research and trials of other countries, to improve our own treatment regimes.

Chemotherapy is a drug treatment usually given intravenously and will treat cancer anywhere in the body. There are also oral chemotherapy drugs. Radiotherapy in contrast, is an x-ray treatment that is localised and targets the cancer cells.

Helen was thanked for her very interesting and informative talk.

Richard Green then spoke about his work for his thesis. He is a student from Surrey University and is preparing a thesis concerning prostate cancer, for his Ph.D. He has spent time visiting 17 of our members, recording the interviews and incorporating the information anonymously into his research project. He said that he would return again at a later date to give us another update.

NEW PROSTATE CANCER SUPPORT GROUP IN BUCKINGHAMSHIRE

One of the guest speakers at our June 2014 meeting was Sue Howse of the Macmillan Foundation. Our chairman recently received some news from Macmillan that they have established a new support group in Buckinghamshire, and our chairman has written the following report about their group, that you will find of interest:

" Many of you may remember Sue Howse who was one of the Macmillan team who came to talk to us about their wellness and exercise program a couple of months ago. Sue covers the East Berks and Bucks area and had been overwhelmed by requests for help from men who had prostate cancer – mostly diagnosed and treated via Wexham Park Hospital.
She was very impressed with our Group and it gave her the impetus to set up their own PCSG. I was invited to go and talk to their second meeting. Their group very closely reflects ours in its early development – initially just a group of 6 or 7 men (with a core of 3 or 4) who are very enthusiastic to start up something that could be of benefit to many. They have, as we did, a wide range of both age, stage of diagnosis and treatments undergone. It was good to share in their enthusiasm and to hopefully point them in the right direction of needing to form a management committee, sourcing initial funding etc. It did make me remember the small beginnings from which our own group has grown and how much we owe to the 'original few' who set up the RPCSG.
I offered this new group our full support. I have no doubt they will flourish. If you know of anyone with prostate cancer in their area that might gain benefit from the new group, then please let me know and I can give you further contact details. "

ABOUT-TURN ON SELENIUM AND VITAMIN E SUPPLEMENTS

Studies done in the 1980s and 1990s suggested that vitamin E and selenium each somehow provided protection against prostate cancer. The Selenium and Vitamin E Cancer Prevention Trial (SELECT) was started in 2001 to see if that was true. The 36,000 healthy, middle-aged volunteers were divided into four groups. Each man took two pills a day: 400 international units (IU) of vitamin E plus 200 micrograms of selenium; vitamin E plus a placebo; selenium plus a placebo; or two placebos. Neither the men nor their doctors knew who was taking what.

Although SELECT was supposed to last until 2011, it was stopped three years early because neither vitamin E nor selenium were showing any benefit—and there were hazy warning signs they might be doing some harm.

A team of researchers from across the U.S. looked specifically at almost 5,000 of the SELECT volunteers who sent in toenail clippings when they joined the trial. Toenail clippings are a great way to measure how much selenium is in a person's body. The new study showed some concerning interaction between the two supplements:

- Taking vitamin E alone boosted the risk of developing high-grade prostate cancer, but only in men who started the study with low selenium levels.
- Taking selenium, either alone or in combination with vitamin E, increased the risk of high-grade prostate cancer in men who started the study with high selenium levels, but not in those with low selenium levels.
- Among men who didn't take either vitamin E or selenium, those who started the study with high selenium levels were no more likely to have developed prostate cancer than men who started it with low selenium levels. (This means the culprit is added selenium from supplements, not selenium from food.)

The moral of this report is that any claims of benefits from dietary supplements must be ignored unless large, controlled, and well-

conducted investigations confirm such benefits.

You can read more about this topic at this web page:

http://www.health.harvard.edu/blog/selenium-vitamin-e-supplements-increase-decrease-prostate-cancer-risk-201402287059

RESEARCH INTO A WASHABLE INCONTINENCE EPAD

A research project is starting at Southampton University into the development of a washable incontinence pant for men. Our chairman has distributed some information on this by email to our members, as the university is seeking volunteers for the project. The university is seeking men who have had treatment for prostate cancer and who need to use an absorbent product for moderate to heavy leakage during the nights. The email sent by the chairman had an attachment that was a brief description of the product, and the details of contacting Bridget Clancy if you are interested in taking part in this project (b.clancy@soton.ac.uk or 02381 204141).

I will make a point of following this up in the future, because anything that the university develops could be of value to our members, and hopefully there could even be something for day time use as well.

FUTURE MEETINGS

The meeting on 5th December will be the Christmas Supper and Social. This was a very popular event last year, and we hope will be similarly well attended this year. The venue is again the St. Andrews Church hall, starting at 18:30. There will be a buffet meal prepared by a catering company, a quiz, and a raffle whose takings will go to the Group's fund to help us to continue our activities. The committee members will again decorate the hall in the festive spirit.

The Chairman has asked for those of you who would like to come to this event, to let him know by the 25th November, so that we can confirm the numbers to be catered for.

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