

PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group (RPCSG)

Issue 29: October 2013

EDITOR'S FOREWORD.

I had a radical prostatectomy in January of this year, and since then have been reading a lot about penile rehabilitation following surgery. I came across the phenomenon of penile shortening which can be a consequence of surgery, and is a consequence that nobody ever tells you about beforehand. The following web page is a useful description of the phenomenon:

<http://myprostedoc.blogspot.co.uk/2011/06/shortening-of-penis-after-prostatectomy.html>

Shortening is thought to be caused by fibrosis or non-use atrophy. If a penis is in a flaccid state for a prolonged time, thought to be around two years, any shortening can become permanent. The typical time to recover erectile function is up to two years, and it is best to avoid a flaccid state for this length of time. Many articles recommend a VED (Vacuum erection device) to increase blood flow and exercise the muscles, as an aid to both the return of erectile function, and to prevent penile shortening.

This web page document recommends the early use of a VED:

<http://www.nature.com/ijir/journal/v19/n5/pdf/3901561a.pdf>

as does the Prostate Cancer UK website, in page 41 of their booklet 'Prostate Cancer and your sex life' available to download via this web page:

<http://prostatecanceruk.org/information/our-publications>

I decided to obtain a VED as it could be beneficial and is non invasive, and if used properly is harmless. I managed to obtain one in March this year and it has been getting to grips with me ever since. The choosing and obtaining was not without hurdles, and the process would have been

easier if I had known earlier what I know now. I thought that I would document my experience of choosing and obtaining a VED for the benefit of any member who also wants to obtain a VED. My document is titled 'Choosing and obtained a vacuum erection device'.

Note that another group member has written a report on his experience of using a VED, titled 'The astonishing potency of a vacuum'. Eventually both that document and mine will be available via the RPCSG web site, but if anyone would like a copy now, of either or both of these documents, please email me.

THE OCTOBER MEETING (4th October 2013).

The guest speaker was Dr. Helen O'Donnell, an oncologist consultant (Chemotherapy and Radiotherapy) at the Royal Berkshire Hospital. She explained that she would give a general account of all of the functions of the unit, and invited the audience to ask questions at any time. There were many questions from the audience, who greatly appreciated the opportunity to raise questions as they arose.

The work of the unit is changing as we learn more about improvements in imaging (e.g. functional imaging), radiotherapy, and hormone therapy. There is an ever-growing spectrum of treatment strategies aimed at improving patient selection, treatment outcomes and disease evaluation.

Helen then described functional imaging. (MRI). The process is rather noisy but is very good at highlighting soft tissue, and is better than ultrasound or CT scanning. After negative biopsies, we can carry out functional imaging scans that will also help

to direct further biopsies to the appropriate areas.

PET scanning is a functional scanning development that is not yet common-place, and looks for areas of increased cellular activity which can indicate the presence of cancer, and is helpful for scanning the lymph glands and pelvic areas.

Thanks to new scanning developments, we can be more precise in the locations of cancer and can carry out image-guided radiotherapy. Previously fiducials (three gold pellets) were implanted into the prostate as markers that were used to ensure accurate targeting of beams into the prostate, but the newer radiotherapy machines with scanning techniques no longer need the fiducials, and more accurate targeting allows higher radiation doses to be used safely and with reduced side effects.

Work is ongoing to determine whether the lymph glands should be radiated as well as the prostate, and to determine whether this leads to better long term outcomes.

Another development is volumetric treatment (VMAT) whereby the dosage can change as the generating head moves around outside the body. This is likely to become the standard technique.

In reply to a question about HiFu, Helen said that although this treatment has been around for a while, there has not been much usage and no evidence that it is suitable as a primary treatment instead of radiotherapy.

A trial found no significant difference in the long term (15 years) outcomes between brachytherapy and surgery.

If there is a recurrence after brachytherapy then prostate surgery is not common and is not ideal, but is a possibility if the cancer is again in the prostate, as is HiFu treatment. She advised against taking recurrence into consideration when deciding on a treatment at the outset – the priority is to select the most appropriate treatment at the time, based on lifestyles and possible side effects.

Hormone treatment is a good first-line treatment for patients who prefer drug treatment, and new drugs are appearing.

Hormone treatments lower testosterone levels or reduce the effect of testosterone, but prostate cancer cells become resistant, when chemotherapy can then be applied.

The drugs Abiraterone and Enzalutamide have come into use in the last 2 or 3 years. They tend to be used in situations where prostate cancer has returned, or has spread to other parts of the body. Abiraterone was originally licensed for use only after chemotherapy, but is now licensed for use before chemotherapy treatments, which is welcome as it has less side effects than chemotherapy drugs.

The use of Abiraterone before chemotherapy is not approved by NICE, however one can apply to the Cancer Drug Fund for it to be funded before chemotherapy. The hormone drug Enzalutamide is not approved by NICE, and its licence is for use only after chemotherapy, but again one can apply to the Cancer Drug Fund. It is not available if Abiraterone has already been used – it has to be one or the other.

Helen then described some clinical trials currently taking place to find out:

- Are fewer doses of higher radiation better at curing than the standard treatment?
- Is it safe to give high doses to the prostate, and lymph glands, and what side effects there are for giving radiotherapy to the prostate and pelvis?
- Should all patients have radiotherapy after surgery?
- Comparing hormone injections against oestrogen patches
- The use of hormones, chemotherapy, Abiraterone and radiotherapy in high risk or metastatic diseases.

One of Helen's slides concerned Intensity Modulated Radiotherapy (IMRT) and contained a link to a Youtube video, but she could not show the video as we did not have internet access at the meeting. However it can be seen by clicking this link: http://www.youtube.com/watch?feature=player_detailpage&v=eZS6DVGBx0k#t=127

Helen was thanked for her very interesting talk, and was presented with a bouquet of flowers as a token of appreciation.

FUTURE MEETINGS

The November meeting will be on the 1st November when the guest speaker will be Dr. Steve Foley, an incontinence expert.

At the December meeting on Friday 6th December we will be hosting our annual Christmas Supper and Social at St Andrew's Hall. An event not to be missed!!

FUTURE EVENTS

None planned

NEW MEMBERS.

We welcomed four new members at the September meeting.

All members are welcome to get in touch with any of the support contacts below should they want to discuss any matter relating to prostate cancer.

SUPPORT CONTACTS

For any member who would like some help or support from the Group, or simply would like to chat with someone – perhaps another member who is or has been in a similar situation – any of the members below can be contacted:

Steve Allen	01189 266 747
Ian Forrester	01189 789 857
Keith Jackson	01189 842 999
Paul Sefcick	01635 34778
Graham Cook	01189 691 668
Steve Parkinson	01189 785 268

RPCSG WEB SITE

Additions and improvements to the draft web site continue to be made. It is hoped to give a demonstration of the web site at the start of the December meeting – to be confirmed.

INTERESTING ARTICLES

A member has kindly sent to me an article from a magazine that gave some information on advanced prostate cancer. The magazine is called CHOICE and can be obtained by subscription or purchased in larger branches of W H Smith and many independent newsagents. It is a lifestyle magazine aimed at the over fifties, and contains interesting lifestyle articles concerning among other things, health, travel, finance, gardening, and care. The magazine has a web site at: www.choicemag.co.uk

The August 2013 edition contained an article titled 'The Prostate Cancer Lottery'. I am grateful to the Editor of CHOICE for permission to use the text of the article in this newsletter, and also many thanks to the journalist Judy Hobson who authored the article and also gave permission to use the text, that she said took some time to research and prepare. Judy is a member of the Guild of Health Writers and as well as other journalistic awards, Judy won an 'Excellence in Cancer Reporting Award' in 2009.

The article said that about half of men in their 50's will have some form of cancerous cells in their prostate, but most will grow slowly and are unlikely to cause problems. About 40% of them will go on to develop a more aggressive form of the cancer than can spread to other parts of the body. In the UK, prostate cancer has not had as much attention or research funding as breast cancer and other complex diseases, and has a higher death rate than neighbouring countries such as Ireland, Belgium, France and Spain. In the provision of new treatments for advanced disease, the UK lags behind France, Spain, Germany, Italy and Sweden. The article then reported on Doctor Heather Payne, a consultant oncologist at University College London Hospitals' Trust. She specialises in the management of urological cancers and is involved in clinical research. She said that prior to 2004 it was thought that nothing much could be done for the advanced disease, but in the last three to four years a range of new drugs has emerged that will improve quality and duration of life. A problem up to April this year has been that NICE (National Institute of Health and

Clinical Excellence) was operating on a regional basis, leading to men not being able to have access to some drugs that men in other areas of the country were able to have. There is now a single list for England, which means the end of the postcode lottery. Two of the newer drugs, Cabazitaxel and Abiraterone, are now on the list. Enzalutamide is another new drug that needs to be added to the list. Research is under way to make use of the drugs Abiraterone and Enzalutamide earlier in the disease. Dr. Payne says that we need to identify biological markers to determine which men are more likely to respond to a particular drug, and hence develop more personalised medicine for those with advanced prostate cancer. She says that we have yet to see the full impact of the new drugs, and we need to fight for the drugs to be given earlier.

The article then quotes Professor Roger Kirby, based at The Prostate Centre in London Wimpole Street. Dr. Kirby aged 62, has removed more than 2500 prostates in his career, and said that some doctors are not aware of the newer treatments because it can take time for the information to get through, and thinks that we need to encourage the government to be less negative about prostate cancer, and for it to be given greater priority. He said that spending on breast cancer is five to ten times greater than it is on prostate cancer. He had been monitoring his own PSA level, that helped him to diagnose himself with prostate cancer, and he continues to monitor his PSA level after having a radical prostatectomy. He thinks that more men should be aware of their PSA level, as only about 7% of men are tested for their level.

The article ended by Dr. Kirby expressing concern about the situation after the Government funding of the Cancer Drugs Fund ends in 2014, however since the article was written it was announced on the 28th September by the Government that the funding for the Cancer Drugs Fund is to be continued for a further two years with a funding of £200 million per year, until March 2016, and that "we are partnering with Cancer Research UK to conduct new research into the effectiveness of cancer drugs".

The Cancer Drugs Fund has been running since 2010 and has helped more than 34,000 people. It gives access to drugs that are not available on the NHS list due to being too expensive or not been shown to make a big difference. You can read about this extension at this web page: <http://www.cancerresearchuk.org/cancer-info/news/archive/cancernews/2013-09-28-Government-announces-extension-of-Cancer-Drugs-Fund?view=rss>

Also there is a press article at this web page: <http://www.expressandstar.com/news/uk-news/2013/09/27/cancer-drugs-fund-extended/>

AND FINALLY...

Last month I mentioned that Michael Parkinson had prostate cancer. Just after that the actress Linda Bellingham (remember her as the Oxo mum in the 80s adverts?) has contracted an undisclosed type of cancer, but we can be sure that it is not prostate cancer. A common point with both of these people is that they were both told that they would not die of the cancer. I find it strange that consultants can be so definite – they are usually quite reticent about predicting outcomes. Quite rightly too, as some people react in strange ways to prognoses. There are stories about people who have been given very poor outlooks only to find later that the prognosis was wrong. In the case of comedian Dave Ismay, he was told that he had liver cirrhosis and only three months to live. He then spent his savings including buying a very expensive motor car, then was told that his diagnosis was wrong and he had a non-life threatening aneurysm, and a treatable hereditary condition called haemochromatosis. His story can be seen here:

<http://www.dailymail.co.uk/news/article-1331754/Comedian-Dave-Ismay-spends-life-savings-told-3-months-live.html>

In another story, an anonymous New Zealand man was told that he had two months to live due to cancer in the heart tissue. He sold his home, and spent or gave away all of his money and got into debt by

\$80,000 due to a failed business. The story is on this web page:

<http://www.theblaze.com/stories/2012/06/18/couple-goes-broke-after-incorrect-cancer-diagnosis-leads-to-80k-bucket-list-spending-spree/>

In both cases it must have been a relief to be told about an incorrect prognosis, but is probably offset by the needless loss of money!

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If any member without internet access would like a printed copy of any article referenced in this newsletter, please contact me – by telephone (see in Support Contacts) or by asking a friend or relative to email me.

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