

PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group Issue 20 November 2012

Editorial Comment

To ensure the Newsletter continues to be relevant, feedback is welcome from Members. You may do this by email to the Editor at ken.davik@yahoo.co.uk or, alternatively, write to the Chairman at his home address.

New Members

Welcome to Mike Linstead who joined in August, Jean and Laurie Fineman who joined in September ; Linda and Ken Burrows who joined in October , with Steve Parkinson and Graeme Mawbey joining in November

Activities in the last month

The November meeting took place on the 2nd when we were due to have Darren Breen and Thanjut Thevah from iMEDicare talking to us about Prostate treatments and ED (Erectile Dysfunction) and potential, commercially available solutions, in particular vacuum devices which iMEDicare market

In the event, due to Darren's travel problems the talk was delivered very professionally by Thanjut.

(Before attempting to summarise this 30 slide presentation I should like to say any innuendo in this article is entirely due to incompetence and bad guidance from my mentor Bill Shakespeare – Ed.)

The talk began with some familiar pictures of where the prostate is situated and some more detailed sketches of the organ itself and things it is connected to (some would say “to which it is connected”). We were reminded of some of the statistics relating to PCa with 40,000 being diagnosed each year with 10,000 deaths. (to put this into some sort of perspective, in the six years of the Group's existence we have “only”, but sadly, lost 6 Members out of a current male membership of nearly 100. Thanjut reminded us that the probability of having cancer increases rapidly after the age of 50, a further stimulus for our Awareness initiatives.

All of the treatments for PCa were mentioned, ranging from a Radical Prostaectomy through radiation to complimentary therapy, as a precursor to telling us that ED affects mostly those who have had a radical

even with nerve sparing techniques.

The importance of “use it or lose it” (Confucius he say) where nature/evolution has resulted in spontaneous/morning erections being in men’s’ genes to help and it was suggested that use keeps penile tissue healthy.

Thanjut went on to describe various ED therapies for those with ED issues post treatment., which are :-

- Vacuum erection therapy
- Oral pharmacology, for example Viagra and Cialis.
- Urethral suppositories
- Penile injections – ouch!
- Penile prostheses – oh!

The talk now became slightly more commercial, but acceptably so, as the pros and cons of vacuum devices therapy were outlined which include:-

- working with the bodies natural functions
- therapeutic effects for the vascular system
- non-invasive
- minimal side-effects

There were then sketches of the cylinder in, place then pumping taking place and then sealing with a ring (there is even an electric version.)

There was then a table suggesting that vacuum therapy was the fastest, the most predictable for results and , if you had to pay for it, the cheapest over three years

Thanjut then showed a neat slide with a quotation from Hippocrates (of oath fame) ca.410 BC “Above all.....do no harm” This reinforces the **iMEDicare** view that their vacuum devices are a conservative treatment regimen ,which minimises risk and expedites recovery, at minimum impact on patient health.

A list of “contraindications, ie don't do it, was then described which included:-

- Sickle cell disease
- Hodgkin's Lymphoma
- Haemophilia
- Polycythaemia

Which are some examples of abnormal physiological conditions, especially of the blood.

So what are conditions for success, apart from any contraindication constraints; here are at least three things for vacuum therapy to be successful:-

- a motivated patient
- a willing and motivated partner
- the knowledge and then development of the correct techniques for its use

It was suggested that with all three present, there could be a 90% success rate.

The devices are available on the NHS for Schedule 11 patients., which is understood to apply to PCa “victims”with ED issues.

There is mounting evidence that the use of such a device prior to radical surgery, not only improves the time to successful intercourse post surgery, it also reduces the incidence of non-use atrophy (use it or lose it) and assists the recovery of erectile function post-surgery. But clearly this depends on individual cases and circumstances.

Thanjut closed with a “slide” saying “Enjoy your Rumpy Pumpy” - I did hesitate slightly before including this but I enjoyed the play on words, so I relented.

The presentation was well received with quite a few questions primarily of a clarification nature.

For those readers that like the stats. the meeting was attended by 41 Members including 11 ladies , with 13 Committee Members/wives within the overall total.

Finality don't forget to read the disclaimer at the end of the newsletter!

Awareness

No significant specifics here, but remember to keep your friends and relatives informed “early detection is good”.

At the Christmas social look out for those Members who are in the Movember moustache growing initiative, and bring a dry, blunt razor!

Forthcoming Events

7th December - The Christmas Social: details have been sent to **all** Members in a separate email, further reminder will be sent in the middle of the month.

2013 Meetings – For Members looking ahead, a full list of dates will be sent out separately at the end of

2012 by email and post, as appropriate. It looks as if bank holidays will not interfere, so the meetings will be on the first Friday in the month

4th January 2013 – Historically we have been hit by either post-Christmas blues, bad weather or both, particularly snow and ice making it risky for Members travelling. **So..... there will not be a meeting in January.** But, and there often is one, the hall will be manned by a skeleton Committee team in the event **new** Members come seeking support and help.

1st February, etc– TBA

Support

As you should be aware from issues of Pharos, there is a set of ‘phone numbers on a credit card size laminated card, available for Members to take at the monthly meetings. These are for Members’ use for seeking support.

For those who do not have the card, the names and numbers are: -

- ◆ Steve Allen 0118 9266 747
- ◆ Bill Forfar 0118 9619 655
- ◆ Ian Forrester 0118 9789 857
- ◆ Keith Jackson 0118 9842 999
- ◆ Paul Sefcick 01635 34778
- ◆ Graham Cook 0118 9691668

Archives

When Pharos was issued quarterly it included a list of perhaps interesting things which were Archived. When we went to a notionally monthly issue Members did comment that this was not necessary and in response it was agreed the Archive list would be included about once a year.

The list contains some articles of a personal and sometimes graphic nature relating to Members’ experiences. Bill Forfar maintains a file, in hard copy form, of Members’ experiences and this is available at each RPCSG meeting for Members to “browse” through.

If you wish to have a copy of **any** in the list please let the Editor know if you have Internet access and from the Chairman if not.

(Please be aware that links sometimes “timeout”, i.e. don’t work, as I have found in the past.)

- Travel Insurance with a Bank - May 2010 (Describes a Member’s experience in evaluating and setting up a new account type with a Bank which offers a range of benefits including travel Insurance)
- Before and after a Radical Prostatectomy by robot, Parts 1 to 4 - May 2010 (Written by Member provides a comprehensive outline of “Approaching the Operation part 1, In Hospital

part 2, Back home part 3, Incontinence part 4 version 2, July 2010” and covers experiences and practical advice.)

- The astonishing potency of a vacuum! Version 3 – October 2010 (Describes a Member’s practical experiences in using a “mechanical aid” but **please note** as of the November 2012 meeting this document is being updated.)
- You Are Not Alone (YANA) - 30 pages or so, a document written by an American diagnosed in 1996 and at publication, still writing, this is the latest update in 2010
- RPCSG Constitution June 2011
- Mr Peter Malone’s presentation on the 1st July

2011, pictures only, no text

- Pharos, the Group’s Newsletter - June 2009 to current.

Disclaimer

The newsletter does not offer medical advice. Nothing contained on the newsletter is intended to constitute professional advice for medical diagnosis or treatment or to advocate or recommend the purchase of any product or use of any service or guarantee the credentials or appropriateness of any health care provider. Members are strongly advised to consult with an appropriate professional for specific advice tailored to their situation.