# *PHAROS*

***A beacon of hope in the darkness***

***Newsletter of the Reading Prostate Cancer Support Group (RPCSG)***

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## EDITOR'S FOREWORD.

At the start of the February meeting we were again treated to the delightful cupcakes made by Laura, the daughter of one of our members.

*A photograph of my cake, taken a few seconds before I ate it!*

The February meeting was very well attended by 72 people, who were all treated to a very informative and entertaining presentation on incontinence by Mr. Steve Foley. A summary of the presentation is provided later in this newsletter.

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Some good news is that the fund raising initiatives for the 'Robbie the Robot' appeal have paid off. The money raised to purchase the machine has met the target and the machine is now to stay at RBH. The Robbie (a robotic laparoscopic Da Vinci) machine was under a contract that was due to expire and that would have seen the transfer of the machine by its owners to another hospital, leaving RBH without any machine of this type. The money raised has enabled the outright purchase of the machine for its sole ownership by, and use at RBH. You can read a media report on this machine at this web page:

http://www.getreading.co.uk/news/local-news/robbie-robot-stay-royal-berkshire-6393169

*Mr. Adam Jones with Robbie and supporters*

## REPORT ON THE FEBRUARY MEETING

The meeting on the 7th February featured a talk by Mr. Steve Foley on incontinence. He was most enlightening and informed us of the types of incontinence, the causes and treatments of them.

He started by challenging us as to how many times per day a visit to the loo for urination is normal. The answer is eight times during the day, and only once during the night. Any more than these is not normal and usually indicates a problem. Also important is the time between needing a visit, and getting there - you should be able to retain urine before getting to the toilet.

Mr. Foley described four types of incontinence:

➪Urge - a misbehaving bladder that starts to squeeze before you are ready

➪Mixed - a combination of 'urge' and stress incontinence (leaking urine when sneezing, coughing, fast walking, etc)

➪Overflow - having a full bladder all the time leading to leakage

➪Climacturia - releasing some urine at orgasm.

Urge incontinence can be treated with tablets, or injections of collagen. The latter needs to be repeated as the body eventually absorbs the collagen.

The incidence of incontinence has been measured by various organisations with results varying between 2.5% to 80%. This variation illustrates the fact that measuring incontinence is difficult because of differences in the definition of incontinence, differences between patients, and in practises and techniques. Also changes in techniques over time can change the measurements, e.g. nerve sparing and bladder neck sparing treatments.

A sample of 500 patients who had prostatectomies were given questionnaires about incontinence, and a summary of the findings is shown below, of the percentage success of treatments as measured by pad usage per day at 3 and 24 months after treatment:

| Pads/day | 3 months | 24 months |
|---|---|---|
| 0 | 33.7% | 80.0% |
| 1 | 37.0% | 18.5% |
| >2 | 29.1% | 1.5% |

This shows a high level of continence regained after two years.

Surgical treatment is not generally carried out in the first year after any treatment course has been given.

The definition of incontinence is not precise, e.g. it could be defined as 1 pad per day, or 2, or more.

## Preventing post-RP incontinence.

Continence success depends on several factors, such as age, stage of cancer, technique (e.g. nerve sparing, bladder neck sparing), surgeon's experience, and previous treatments (e.g. TURP or radiation).

## Pathophysiology.

Post-RP incontinence is caused by:

- Bladder dysfunction
- Obstruction
- Sphincter dysfunction - may have weak muscles, or the sphincter may be damaged.

## Stress incontinence

If suffering incontinence to the extent of 3 - 4 pads/day one year after RP surgery, it is likely that the sphincter is good but the muscles are damaged. If you need to use a conveen (external catheter) then it is likely that the sphincter is damaged.

## Intervention.

The treatments for incontinence include:

✶Physiotherapy

✶Urethral bulking agents such as collagen, which will partially close the urethra and so help to relieve incontinence. The advantages are that it is easy to apply, is minimally morbid, and does not 'burn any bridges' for other treatments.

✶Sling. This is an operation to implant a mesh that is tightened and then secured such that it lifts a sagging pelvic floor muscle and so helps to restore continence. It needs only one night in hospital, and scar tissue retains the mesh in place. You must keep your legs together for several weeks! Success rate is greater than 58%. Previous radiotherapy may be a risk factor.

✶AUS (Artificial Urethral Sphincter). This is a device consisting of a cuff mounted around the urethra, a small reservoir of sterile fluid, and a manually operated pump placed inside the scrotum. The patient operates the pump a few times to inflate the cuff and allow the passage of urine, and then the pump relaxes after about 90 seconds so that the cuff tightens and again seals the urethra. If a patient is using more than 5 pads per day this indicates that the sphincter is damaged and the AUS can be considered.

**Disadvantages** of the AUS are that it is not durable, requires some manual dexterity, and the subsequent insertion of instruments into the urethra via the penis is not normally possible. The failure rate is about 50% after 5 years due to mechanical failures.

**Advantages** are that its success rate ranges from 59% - 90% judged as using 1 pad per day or less. A recent development is a two-piece device (the pump and reservoir are combined) and so is more reliable, with failure rates reduced by about 50%. Also further fluid can be easily added to the reservoir if more cuff tension is needed.

**PPI Surgery.**

Post-prostatectomy incontinence surgery is not normally attempted within 12 months of any other surgery. Surgeries to be considered are:
**AUS** for moderate to severe incontinence
**Sling** for mild to moderate incontinence
**Bulking agents** for mild to moderate incontinence, but this can be a less effective option than other treatments.

There were then some questions from the audience:

Q> What are the reasons why men have to visit the toilet during the night?
A> Kidneys may not be working as well as they should, or bladder irritation. There may be other causes such as peripheral oedema.

Q>What are the reasons for a diverted flow?
A> Usually due to turbulence in the flow caused by a partial blockage in the urethra (Editor's note: Turbulence can result in a urine stream that is split, angled, or 'shower head', and the causes of turbulence include a urethral stricture).

Q> After prostatectomy 14 years ago, I carried out pelvic floor exercises, regained continence then ceased the exercises. Any advantage in restarting them?
A> Definitely, yes. A study found that 65% of significant incontinence problems were cured with physiotherapy.

Q> Does bladder cancer cause incontinence?
A> About 50% of cases with bladder cancer suffer from incontinence, of which many can be cured by medication.

Q> Can the artificial sphincter be triggered accidentally?
A> No. Note that the device is inoperative when installed, until it is activated a few weeks after installation.

Q> Are hot flushes when taking Zoladex an indication of a weakness?
A> To help to determine the treatment of flushes, it is a good idea to make records of occurrences. A flush duration of two hours or more is too much.

Q> Drugs and retention.
A> Tablets should not normally cause urinary retention.

Q> Scar tissue and AUS
A> An AUS is not advisable if treatment of scar tissue is being carried out, as it is not a good idea to be regularly passing instruments through the artificial sphincter. Scar tissue usually stabilises in time, then an artificial sphincter can be fitted.

Mr. Foley was sincerely thanked by the Chairman for an excellent and entertaining talk.

## NEXT MEETING

The next meeting will be on Friday 7th March. This will be the Annual General Meeting of the Group which we are obliged to have under our Constitution. Details of this will be sent you soon. As well as this we will be having some updates on what is happening with both prostate and bladder cancer in our area. There will be ample opportunity to talk together before and afterwards.

## FUTURE EVENTS

The month of March 2014 is a national 'Prostate Cancer Awareness' month and there are two events in which we would like to participate. We have only recently found that these events are on consecutive days, but we still intend to go ahead with them both. These events are:

- On Friday 14th March we will be holding a Prostate Cancer Awareness event in Reading at the Broad Street Shopping Mall (previous named the Butts Centre). We held this event successfully in 2013 and this forthcoming event should be even better because our stand will be at the bottom of the escalators which is a much more prominent position than last

year when we were outside T K Maxx. Again we request volunteers for this stand, so if anyone can help by attending for a two hour session during the day, it would be much appreciated. Please contact the Chairman on ChairmanRPCSG@yahoo.com if you are able to spare some time for us. This is not a fund raising session; it merely involves responding to anyone who shows an interest in the stand, and approaching appropriate people to see if they would like to have some information about prostate cancer.

- A fund raising collection will be held on Saturday 15th March 2014, outside the Madejski Stadium football ground, and will involve holding a collection box and receiving donations. We would greatly appreciate any volunteers for this occasion - if you can help please email the Chairman on ChairmanRPCSG@yahoo.com

  The collection will take place between 12:30 and 15:00. The money collected will be for the RPCSG and used for Group purposes, which is essentially to promote awareness of the cancer, and the provision of information and support. We will be joined by some of our friends from the Bladder Cancer Support Group and will be 'dividing the spoils' from this venture.

## AND FINALLY...

Imagine yourself in this situation. You are in a public toilet using a urinal, and there is someone using the one next to you (Don't you just hate it when there is someone next to you?) Imagine your reaction if the man next to you speaks to say that your urine flow seems slow and weak, and that it could indicate a urinary problem. I think that I would try to put a big distance between him and me as soon as I could.

The above situation is the one that Colin Outhwaite found himself in, in a urinal in a school at a charity event. Colin is the Father of actress Tamzin Outhwaite. Colin took the stranger's advice and visited his GP, and it almost certainly saved his life. The GP referred him for tests which found that he had aggressive prostate cancer. That was five years ago and Colin was treated with a radical prostatectomy, and he has now fully recovered. Once again this is an example of a man being diagnosed by chance, and the outcome of that chance urinary encounter could have been so different if Colin had not acted.

You can read more about Colin's experience here:
http://www.thetimes.co.uk/tto/public/timesappeal/article3955560.ece

You may also like to watch this Youtube video of a live interview with Colin and Tamzin, and also Drew Lindon of Prostate Cancer UK. This includes an account of Colin's experience, and a general discussion of prostate cancer:

http://www.youtube.com/watch?v=Mf2zRpEKtEc

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