

PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group (RPCSG)

Issue 95: October 2019

Website: www.rpcsg.org.uk

THE OCTOBER MEETING

The Chairman Chris Addison welcomed all to the meeting including one new member. He mentioned the fact that the Reading Lions Association is holding its annual free PSA testing on the 16th November at the Rutherford Centre. He also said that the Christmas Social will be on the 6th December and that the cost is £20 per person. (See below for further details).

Chris then introduced the speakers for the evening, who were Beverley Skelton and Tessa Martin. Both are very experienced Oncology nurses. Beverley worked at RBH and is now in a private practice, whilst Tessa works in the Urology unit at RBH. The session was an Open Meeting and members had previously been asked to send any questions for answers to be given anonymously.

Beverley and Tessa first explained PSA measurement and Gleason score. These are two topics that raised several questions before the meeting.

PSA stands for Prostate Specific Androgen which is a protein produced by the prostate gland and which circulates the body in the blood stream. Prostate glands produce a level of PSA and usually the amount increases with age. Beverley showed a slide giving the normal levels by age:

40-49 less than 2.5
50-59 less than 3.5
60-69 less than 4.5
70-79 less than 6.5
Over 80 below 20

A simple blood test can measure the amount of PSA in ng/ml. When cancer is present it can result in an increased level of PSA but it is not a good indicator of cancer and is not definitive. An increased level of PSA can also be caused by several things, including infections, ejaculation, exercise (cycling, running), catheter / cystoscopies, DRE (Digital Rectal Examination), prostate biopsies and drugs (e.g. finasteride).

PSA however is a very good marker to measure the progress of cancer after treatment.

A question was raised about the level of PSA after treatment, to which the response is that if the PSA is rising, the doubling time is important. For a man in his 50's if it doubles in about a year this could indicate a problem.

On completing a course of hormone treatment the PSA can rise as it settles to a post-treatment level.

PSA never settles at zero as there are some other glands that produce very small amounts of PSA, e.g. the pituitary and adrenal glands.

The nurses then explained the Gleason score. A patient with a raised PSA is normally given an MRI scan and DRE. A biopsy can then be considered in which a number (usually 10) samples of the prostate gland can be taken and examined under a microscope to assess the degree of cancer cells. It needs the experienced eye of a histopathologist to carry out this assessment and a slide was shown of the appearance of cancer cells of different levels of

aggressiveness. The Gleason scale runs from 1 to 5 but only levels 3 to 5 are considered, so that grade 3 is the least aggressive form of cancer, and 5 is the most aggressive. If a histopathologist sees any cancer cells in the sample he looks at the most prolific type of cells seen and assigns a score to it. If there is a lesser amount of another grade then he assigns a grade to that also. The Gleason score is then stated as the two numbers that were assigned.

For example: If a histopathologist sees only type 3 cancer cells then the score is 3+3. If the most prolific type is grade 3 and there was a lesser amount of grade 4 then the score would be 3+4. Similarly if the majority of the cells were grade 4 and there was a lesser amount of grade 3, the score would be 4+3. Note that sum of the grades is 7 in both of these cases but the 4+3 is a more serious case.

The Gleason scores range from 3+3=6 for the least aggressive cancer, to 5+5=10 for the most aggressive.

A question was raised about rising PSA after radical prostatectomy and hormone treatment. If the PSA has a low level it is difficult to pick up cancer cells by scans as small amounts of cancer cells cannot be identified. A rising PSA could indicate some rogue cells and the speed at which it doubles is important. Note that treatment is never changed on the basis of just one movement of a PSA measurement.

The subject of incontinence was then discussed. As well as a side effect of treatment incontinence can be caused by an over-active bladder or infections, and can be aggravated by things such as tea, coffee and fizzy drinks. If anything in the diet is suspected of causing incontinence, the patient is advised to cut out the suspects one by one and hopefully the culprit will be found. Medical treatments include:

- Staying hydrated
- Treat chronic constipation
- Pelvic floor exercises
- Treat UTI
- Dietary changes
- Medication – Tolterodine, Mirabegron

Surgery with botox can help by paralysing the bladder muscle.

Pelvic Floor Exercises can also help to relieve incontinence. Results are usually obtained in about three weeks.

A question was asked about bleeding from the urethra. This can be caused by damage to the lining of the urethra by such things as infections. A user of Warfarin may experience bleeding, and bleeding could be caused by the use of penile clamp as urine could then be stored along the urethra, increasing the likelihood of infection.

Hot flushes during hormone treatment were discussed. There are caused by the lack of testosterone in the body. Remedies are:

- Try to stay a healthy weight
- Drink 2-3 litres fluid daily
- Avoid alcohol and drinks containing caffeine (tea, coffee, coke)
- Stop smoking
- Avoid spicy foods
- Keep the room at a lower temperature or use a fan
- Use cotton sheets



Tessa (left) and Beverley during their talk

- Wear cotton clothes esp. at night
- Medroxyprogesterone (Provera)

Acupuncture, hypnotherapy and herbal remedies can also help.

The following are responses to questions posed by the audience:

- There is no known connection between prostate cancer and gout.
- The reason for a shortage of Alpostadil (a treatment for erectile dysfunction) is not known.
- Although prostatectomy is considered the Gold Standard there is about 25% chance of cancer recurrence. The outcomes from prostatectomy or radiotherapy are similar and it is difficult to say why occurrence happens - it is possible that it is caused by delinquent cells.
- There seems to be little information about brachytherapy and side effects thus making a treatment decision more difficult . The side effects are difficult to predict, and we do not yet know the survival rates for brachytherapy. However the majority of patients having had brachytherapy do not seem to be unduly troubled by side effects.

The subject of erectile dysfunction was discussed. This side effect can be caused by nerve damage during surgery, or hormone treatment that stops or reduces the testosterone levels in the body.

Treatments include:

- drugs eg Viagra (can now be bought over the counter), Cialis, Levitra
- Alprostadil, given either through injections (Caverjet) or pellets into the penis (Muse)
- Vacuum pumps
- Penile implants
- psychological support.

Beverley and Tessa were thanked for their informative session and were each presented with a gift of appreciation.

NEXT GROUP MEETING 1st NOVEMBER 2019

The November meeting of the RPCSG will be on Friday 1st November at 6:30 p.m. in St Andrews church hall. The guest speaker will be Kate Slater of the Macmillan Trust who will talk about the financial benefits available to cancer patients and carers, from the State, Macmillan and other organisations.

THE DECEMBER MEETING - CHRISTMAS SOCIAL

The December meeting will be our annual Christmas Social. This is always a very popular and most enjoyable event, held in St Andrews Church Hall on the **6th December 2019**. We engage an external contractor Mange Bien who have provided us with an excellent service for many years at our social occasions. A two course buffet dinner and tea or coffee will be served during the evening which will include an enigmatic quiz and a raffle with fabulous prizes at the choice of the lucky winners.

Doors will be open at 6:30 p.m. with the meal being served from about 7:30 p.m. A complimentary drink upon arrival will be served (alcoholic and non-alcoholic options) and due to licensing restrictions you must bring your own drinks (alcoholic or non-alcoholic) for your own consumption during the evening.

The cost of the Christmas Social this year will be £20 per person. This is a little higher than last year as we have requested some festive choices on the buffet menu. The number of places available is limited by the space in the hall so if you want places at this event and have not yet reserved them, please reserve them as soon as possible by contacting our Treasure Roger Bennett at this email address:
saroban@btinternet.com

Payment can be made by any of these three ways:

- In cash at the November group meeting, which will be collected by Graham Cook.
- By cheque made payable to 'Reading PCSG' and posted to Roger at
52 Deanfield Road
Henley-on-Thames
RG9 1UU
- By direct banking transfer. For details of this method please send an email to Roger at saroban@btinternet.com

There will be vegetarian choices on the menu. Please advise Roger if you have any other dietary requirements.

The number of places available is limited so to avoid disappointment please reserve your places as soon as possible. We have to let the caterers know the number of guests attending so places **must be reserved by 27th November**.

JOIN THE COMMITTEE!

The RPCSG committee consists of 12 people and we welcome anyone who is interested to join the committee - we appreciate new members and their ideas. The committee meets about every six weeks or so and you are invited to come along to any committee meeting. You will be welcome as a guest to give us a try and see if the committee appeals to you. Your attendance will be without any obligation for the future. Please email me for details if you would like to attend a meeting.

SECRETARY VACANCY

There is currently a vacancy on the committee for a Secretary. This is not a difficult task, consisting mostly of preparing agendas and minutes of meetings. I will send a copy of the role description to all members and hope that you will be attracted by this role. Please let me know if you are at all interested in this post. It is open to both male and female members.

EXERCISE SESSIONS

You are probably aware of the benefits of exercise that can help enormously to recover from treatment. Several of our members go to sessions and find that they are very beneficial and enjoyable. Macmillan runs two sessions per week run by Tessa Higgins and here is a reminder of the venues to which all of our members are invited:

Mondays at 1:30 p.m. The venue is:
Cotswold Sports Centre
Downs way
Reading
RG31 6SL
01189 414690

First 12 sessions are free then there is a small charge per session.

Wednesdays from 2 - 3 p.m:
Rivermead Leisure Complex
Richfield Avenue
Reading
RG1 8EQ

On-site parking is free but register your car with Reception on arrival otherwise you may be charged for parking.

If you have any queries on these sessions please email them to me.

RPCSG WALKS

The November walk will be on **Tuesday 5th November** and will be a repeat of a previous popular walk. This will start at 10:40 a.m. at the Waterside Park at the top of the A329M and will go alongside the Thames to Caversham and then into Reading, where there will be a refreshment stop. The return will be alongside the river Kennet back to the starting point. The total walk will be about 5 miles.

Directions to the start point are:

Drive towards Reading on the A329M/A3290 and continue to the very end of the road which ends at a roundabout. Turn right at the roundabout onto Thames Valley Park Drive and the entrance to the free car park is about 20 yards on the left. If the car park is full you can continue past the car park entrance and park on the roadside free between 10:30 a.m. and 4:30 p.m. We will return well before 4:30 p.m.

The address of the car park is:
Wokingham Waterside Centre
Thames Valley Park Drive
Earley, RG6 1PQ

All members are invited to this walk. No need to contact anyone, just arrive at the starting point before 10:40.

For your interest, the current plan for the December walk is a very picturesque walk in Burnham Beeches near to Maidenhead. Detail will be in later newsletters.

PREVIOUS WALK.

The October walk was attended by 12 people and was very enjoyable, to the extent that the majority of the walkers voted to walk back to the Cunning Man rather than take a bus that was originally planned.

Photographs taken during the walk:



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DISCLAIMER

This newsletter does not offer medical advice. Nothing contained in 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.

This newsletter may refer to named providers and their products or services, and such reference expresses no inference upon any aspect of any provider's business, services or products, and expresses no recommendation or preference for any such products or services.

DATES FOR YOUR DIARY.

1st NOVEMBER 2019

This group meeting will have the guest speaker of Kate Slater of the Macmillan Trust talking about benefits available to cancer patients and carers.

5th NOVEMBER 2019

This will be the RPCSG walk from Waterside Park to Caversham and Reading.

6th DECEMBER 2019

This will be the Christmas Social event