

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group (RPCSG)

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THE DECEMBER MEETING.

Our Christmas meeting was held by Zoom and began with a Question and Answer session with Beverley providing the answers. Some questions had been submitted in advance and many more arose at the end of Beverley's presentation. Beverley first described the major aspects of prostate cancer and in doing so she answered the questions that had been sent in.

Beverley first showed a slide of the normal levels of PSA by age. A blood sample can have its PSA level measured at the RBH laboratory, the units are ng/ml.

Several activities can temporarily increase the PSA level and so these are best avoided before a PSA measurement:

- Infections
- Ejaculation, exercise (cycling, motorcycling, running)
- Catheter / cystoscopies
- DRE (Digital Rectal Examination)
- Prostate biopsies
- Some drugs (e.g. finasteride).

Because of the above factors PSA is not a good indicator of prostate cancer but it is a good marker to measure the progress of prostate cancer.

After treatment there is no specific target value of PSA, the main consideration is whether the PSA value is stable. Generally a PSA value of about 2 is when other treatments may be considered but other factors are taken into account, such as the Gleason grade at diagnosis, PSA doubling time and prostate volume.

At lower values of PSA it can be difficult to find the cancer. Any cancer has to be large enough to be seen by scans before further treatment can be done. However PET scans can detect cancer when the PSA is less than 2.

Some other glands e.g. the adrenal glands, produce PSA and so the level never reaches zero.

Metastasis is unlikely with a PSA below 15.

Beverley described some scanning systems useful for prostates: PET scan uses an intravenously injected radioactive drug. PSMA (Prostate Specific Membrane Antigen) uses a gallium 68 isotope that binds to prostate cancer cells.

Both of the above are useful when the PSA level rises above 0.2

Beverley then described the Gleason scale of cancer grading. The appearance of cancer cells under a microscope shows the aggressiveness of the cancer, on a grade of 3 (least aggressive) to 5 (most aggressive). The Gleason grade consists of two numbers to be added together, e.g. 3+4. The first number is the grade of the most prolific type of cancer cells whilst the second

Normal PSA 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	

number is that of any less prolific cancer. Gleason 3+4 means that the majority of the cancer cells are grade 3 whilst there are some cancer cells of grade 4. A grade of 4+4 means that all of the cancer cells are grade 4 and no other grade is present.

There is another grading of prostate cancer developed by ISUP (International Society of Urological Pathology). The table on the right shows the ISUP grade corresponding to the Gleason figures. The ISUP grade gives a greater weight to Gleason 4+3 that is a more aggressive situation than 3+4, although in the Gleason scale they are both equal to 7.

Gleason Score	ISUP Grade
3+3 = 6	1
3+4 = 7	2
4+3 = 7	3
8	4
9 and 10	5

Beverley then described the cancer staging system that consists of three parts identified by a TNM system T, N and M.

At my 3 week follow-up following my prostatectomy I was told that my staging was T3a N0 M0 that meant nothing to me as nobody had ever explained it. The number after the T is an indication of how far the cancer has advanced in the prostate, N is either 0 or 1 dependent upon whether any Nodes have been invaded, and M is either 0 or 1 dependent upon whether the cancer has Metastasised or not. The stages are:

T1 is a clinically inapparent tumour neither palpable nor visible by staging
T1c is a tumour identified by needle biopsy

T2 is a tumour confined within the prostate

T3 is a tumour than has extended through the prostate capsule

T3a = Extracapsular extension

T3b = Invasion of seminal vesicles

T4 is a tumour that has invaded adjacent structures e.g. external sphincter, rectum, bladder, levator muscles, pelvic wall.

N1 is when there is metastasis into regional lymph nodes

M1 is when there is distant metastasis:

M1a = Non regional lymph nodes

M1b = In bones

M1c = Other areas

Beverley then dealt with the side effect of incontinence after radical prostatectomy. Most patients are leaky following an RP. This improves over time but can take up to a year to completely recover. After a year treatment may be considered to improve the symptoms.

Incontinence after a few years can have several causes including bladder neck stenosis, urinary tract infection, and very rarely by bladder cancer

Less commonly, radiation can irritate the prostate and lead to permanent damage.

Tests for the cause of incontinence are a urine dip, flow rate, bladder scan and flexible cystoscopy.

Treatments are available for incontinence, these are:

- Pelvic Floor exercises, to be carried out regularly.
- Male sling. These are available at RBH and later slings can be adjusted by the hospital.

- Drinks: Caffeine is an irritant and so one should avoid tea, coffee, coke, blackcurrant, orange and alcohol. Decaffeinated versions are preferable.
- Drugs, e.g. Tamsulosin for the prostate and Vesicare for the bladder.
- A product called Dribblestop is a penile clamp that presses against and closes the urethra. The cost is around £35 and is not available on prescription.
- Pads are provided for patients immediately after surgery or radiotherapy. If incontinence persists then pads or sheaths may be available on prescription after an assessment.
- Bulkamed injection that is a hydrogel injected into the urethra.
- Emsella chair uses a high intensity magnetic field targeted at the pelvic floor muscles and delivers the equivalent of a large number of pelvic floor exercises.

Beverley then described the drug Tamsulosin that is a type of alpha blocker used to treat men with the symptoms of an enlarged prostate (Benign Prostatic Hyperplasia). It is also given to patients for 3 months following a brachytherapy to treat swelling of the prostate that can occur after treatment.

Hot flushes are an unwelcome side effect of hormone treatment due to a lack of testosterone in the body. Ways to help are:

- Try to stay a healthy weight
- Drink 2 to 3 Litres of 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
- Wear cotton clothes especially at night
- Keep a diary to see if there is anything that obviously sets the flushes off.

Other complementary remedies for hot flushes:

- Acupuncture.
- Hypnotherapy.
- Herbal remedies e.g. sage tea, evening primrose oil, red clover.

None of these are evidenced based with minimal research but there is some evidence that they help.

Hot flushes can last for a long time after hormone treatment stops

Prostap - very little evidence to say it can cause some heart rhythm issues so may need a closer eye if this is an issue.

Beverley then invited further questions from the participants. There were many such questions and Beverley gave the following facts in reply:

- Treatment by Prostab may cause lumps in the stomach. This concerns blood vessels and is no concern and will settle down. Injections can alternatively be given in the arm or buttocks.
- A member had been told that his regular PSA measurements will cease after 10 years. A patient can always ask his GP for PSA tests beyond this point. As more younger people are being diagnosed the duration of regular PSA testing will probably have to increase in the future.
- A member wanted to join a trial but was told that he could not. One can look on the internet for current trials that it may be possible to join, and Cancer Research can be approached as they have a database of trials.
- A member enquired about the level of PSA at which investigation would be triggered after radiotherapy. Everyone is different and there is no specific level. If PSA rises many other factors would be considered in any decision, such as original Gleason grade, the starting PSA, the PSA doubling time, and even the patient's age. After the age of 80 the need to investigate becomes less necessary.
- > Developing prostate cancer does not render one more susceptible to other cancers. However the treatment given to prostate cancer many years ago, maybe more than 15 years ago, may raise the risk of other cancers particularly of the bladder, as radiation beams were not as precise as they are now.
- A member had pain and itching in a leg after treatment near his spine. It was explained that this is almost certainly neuropathic pain, which is a type of pain caused by prolonged pressure on nerves that can cause long term changes in the nerves. Itching is a symptom of low grade nerve damage that can take a long time to recover.
- > A member asked about urine leakage when active. Beverley said that the causes could be either in the sphincter muscles or in the bladder whereby the bladder contracts and squeezes urine out. A urodynamic assessment that measures pressure could be carried out that would help to determine the reason for leakage.
- > If Tamsulosin is taken at the same time as drugs such as Viagra, care should be taken as blood pressure will have already been lowered due to Tamsulosin. Viagra, Cialis etc. will reduce blood pressure further and the patient should lie down if feeling faint.
- A member developed strictures about one year after brachytherapy and used Tamsulosin. He was prescribed Mirabegron to relax the bladder but was warned that it could cause retention. Beverley said that retention is very unlikely.
- ➤ Genetic testing is possibly of little value because the presence of any gene associated with a type of cancer does not mean that a cancer will develop. More important is for any man where there is a family history of prostate cancer to seek PSA tests from the age of about 40.

Beverley was thanked for her very useful talk and for the answering of all of the questions.

CHRISTMAS QUIZ

Following Beverley's talk there was a quiz that was enjoyable and a lot of fun. There were ten challenging questions and two members tied with seven correct answers. A tie-breaker was used and the winner announced. Congratulations to the winner and many thanks to Alex Miles for arranging and hosting the quiz.

COFFEE MORNING - 17th December 2020

We will hold a coffee morning on Thursday 17th December from 11:00 a.m. The venue will again be The Flower Pot at Aston. We will observe social distancing and it is an opportunity to just chat with other members about anything.

The postal address is

The Flower Pot Aston Henley on Thames, Oxon RG9 3DG

Directions are to take the road from Wargrave to Henley and at the T junction just before the Henley Bridge, turn right onto the A4130. After about 1 mile turn left into Aston Lane and the Flower Pot is about 1 mile further on.

There is a short cut about 1.2 miles after Wargrave, by turning right into Kenton's Lane, left into Culham Lane, left onto the A4130 and after 300 yards turn right into Aston Lane. You will probably find that a sat-nav takes this route anyway.

Just before The Flower Pot there is an area on the left for free parking, otherwise continue past the pub on Remenham Lane and take the first turning on the right for a free overflow parking area.

I hope to see you and partners at the coffee morning. If you have any queries you can call Richard Brown on 07973 662925.

NEXT RPCSG ZOOM MEETING - 1st January 2021

The first group meeting of 2021 will be held by Zoom on the 1st January. There will be no guest speaker, it will be a social occasion at which you can chat with other members about anything. I will send the link for the meeting closer to the meeting.

Members' partners are welcome also.

RPCSG JANUARY WALK

There will be an RPCSG walk on Tuesday 5th January 2021. The walk will start at 10:45 a.m. at the Waterside Centre car park and go into Caversham and then to Reading. The return will be through the Forbury and the ruins of Reading Abbey and then alongside the River Kennett. It will be about 4 miles. Please bring your own refreshments for which we will have a refreshment stop along the way.

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 or closed 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

A sat-nav using RG6 1PQ will take you beyond the car park turn so use the directions above as you approach Thames Valley Park Drive

All members and partners are invited to this walk. No need to contact anyone, just arrive at the starting point before 10:45.

The December walk alongside the Basingstoke canal was very enjoyable. The weather was great and afterwards several members had lunch at the Barley Mow pub where marquees had been erected for diners. Photographs taken during the walk:





Best wishes for Christmas and a healthy new year.

Steve Parkinson Newsletter Editor. <u>NewsEditorRPCSG@yahoo.com</u>

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

Thursday 17th December 2020 will be a coffee morning at the Flower Pot in Aston.

Friday 1st January 2021 will be an informal group social meeting by Zoom without a quest speaker.

Tuesday 5th January 2021 will be a walk from the Waterside Centre to Reading.