

# PHAROS

*A beacon of hope in the darkness*

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

*Issue 119: November 2021*

*Website: [www.rpcsg.org.uk](http://www.rpcsg.org.uk)*

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## THE NOVEMBER MEETING.

The November meeting was our first meeting in person since the pandemic started. There was a Zoom connection for members who preferred to join in remotely. The session was a Questions and Answers session with the guests of Tessa Martin and Jo Hand.

There were a few technical hitches during the meeting, one of them caused by a failing battery in a transmitter. Many thanks to Tessa and Jo and members, for bearing with us during the slight disruption whilst we sorted out the problem.

The meeting was quite well attended by 21 RPCSG members in person plus 20 RPCSG members by Zoom and 13 guests from other PCSG groups by Zoom. This was a very good attendance.

Chairman Chris Addison gave a welcome to all attendees.

Tessa first explained the effects that the Covid has had on the hospital, that has been a cancellation of many operations due to the risk of catching Covid, and the redirection of many staff to deal with Covid patients. Many more consultations have been carried out by telephone. Jo said that research had closed down whilst staff were redirected to work on Covid patients and that she was looking forward to the imminent reopening of her research work. They are now returning to normal and recommencing the research work. There is more encouragement to patients to investigate matters themselves with the help of the internet and to telephone the hospital in the event of questions, and the research facilities are very interested in feedback from patients.

A question was asked about whether there is anything to counteract hot flushes experienced due to hormone treatment. The question was raised by a member who said that he is suffering from hot flushes that felt strange and uncontrollable, and would sweat excessively for 3 or 4 minutes at a time. He is taking Enzalutamide by injection. Tessa said that Andrew has carried out some sessions on 'Surviving Hormone Therapy' that dealt with some aspects of hot flushes. She said the flushes may go away in time, and that some actions such as wearing light clothing and avoiding caffeine may help. She advised knowing your body if possible, i.e. make a note of your lifestyle and by making changes in lifestyle or diet try to work out if there are any aspects that improve the hot flushes and avoid anything that seems to have an adverse effect on them. Cognitive Behavioural Therapy can help, as can other alternative treatments including acupuncture that has worked for some people. There is a web site listing complementary therapies called 'My Cancer My Choices' that you can read at this web page [My Cancer My Choices](#)

A question was raised about the time period for a patient to be discharged from hospital care to GP care, and the criteria for the decision.

Several factors are taken into account, including the PSA level and whether margins are clear. After surgery a criterion is whether the PSA is increasing, and after radiotherapy whether the PSA is stable. For a patient after a prostatectomy and radiotherapy with stable PSA it could be about five years before discharge.

The criteria for treatment during Active Surveillance was asked.

On Active Surveillance regular MRI scans are performed and they are checked for any changes. Repeat biopsies are carried out and there is a policy for decision on treatment taking all of these factors into account. A patient would not normally be discharged from Active Surveillance unless their PSA had been stable for many years.

In the case of brachytherapy follow-up can be six monthly for 5 years and then annually, However all follow up criteria are being examined and may change.

The NHS operates a national database of PSA measurements. The RBH sends data to this database but has no access to it – the NHS uses it for analysis in data centres including the recommendations for follow up intervals.

A big trial named PROMIS has been carried out, looking at the quality of life when taking Enzalutamide.

The question was asked about Enzalutamide and Prostag. Prostag is an LHRH injection to treat prostate cancer. Enzalutamide is taken in conjunction with hormones when hormone treatment alone is not sufficient.

A member with swollen lymph nodes asked what causes the swelling. Tessa explained that lymph nodes are filters and are affected by cancers but can be affected by other causes as well, e.g. infection (which is the most common cause of lymph node swelling).

A member commented that it can take 3 or 4 weeks to obtain the result of a test. Tessa said that there is a Trust patient portal at which a patient can apply online to see their results themselves including PSA results.

Editor's note: more information is at this web site: [see records](#)

Tessa and Jo were each presented with a bouquet of flowers in appreciation of their handling of the questions.

The Chairman then read some notices about the group:

He invited anyone to join the committee, which is an enjoyable experience without any obligation for any tasks. There are however a few roles that we need to fill so if anyone feels attracted to these then they will be most welcome.

Richard Joyes has run the refreshments coordinator role for some time – this involves just ensuring that we have a supply of tea, coffee, biscuits etc. Richard is now the Treasurer so the refreshment coordinator is a role that is available.

The role of Secretary is available and we have reduced the tasks for this role to just the provision of agendas and minutes for the monthly committee meetings, and the AGM annually, hence this role is now referred to as the Minuting Secretary.

Also the role of Chairman will be vacant from March next year.

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### **NEXT RPCSG MEETING – 3rd December 2021**

For those members who have enrolled, the December group meeting will be a buffet meal on Friday 3<sup>rd</sup> December in St Andrews church hall. We will have all the Covid precautions in place that we took at the previous group meeting.

The doors will be open from 7:00 p.m. and the buffet meal will be served from 7:30 p.m. Please bring your own drinks whether alcoholic or not, for your own consumption. Please also wear a face mask until seated.

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There will be a group meeting on the 7<sup>th</sup> January 2022 in the church hall. There will not be a guest speaker, it will be a general meeting that will be an opportunity to chat with other members about almost anything, hence there will be no Zoom connection. Refreshments will be available.

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### **RPCSG WALKS**

Eight members joined the enjoyable walk in November from the Waterside Centre, to Caversham and the Forbury, and return via the Abbey ruins and the Fisherman's Cottage.



*Refreshments at the Fisherman's Cottage*

The next RPCSG walk will be a circular walk of about 4 miles on **Tuesday 14<sup>th</sup> December** starting at Hambleton with lunch at The Frog as Skirmett. I will send directions and parking information by email to all members nearer to the event.

If you have any queries about the walk please contact Richard Brown on 07973 662925.

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## COFFEE MORNINGS

The November coffee morning was very enjoyable and held indoors at The Cunning Man with 13 members attending.

The December coffee morning would normally be on Tuesday 21st December but this is rather close to Christmas. We propose to combine the walk on **Tuesday 14<sup>th</sup> December** with a coffee morning by rendezvousing the walkers and the coffee crowd for lunch and/or refreshments, possibly at The Frog at Skirmett.

When the arrangements have been finalised I will send the details to all members by email.



*Coffee morning in The Cunning Man*

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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.**

**Friday 3<sup>rd</sup> December 2021** for those who have enrolled, is the Christmas Social.

**Tuesday 14<sup>th</sup> December 2021** will be a circular walk starting in Hambleton.

**Friday 7<sup>th</sup> January** will be an open meeting in the church hall.