

PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group (RPCSG)

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Website: www.rpcsg.org.uk

THE FEBRUARY 2022 MEETING

The meeting in February featured a talk by our Chairman Chris Addison. It was well attended by 28 RPCSG members and 3 people from other prostate cancer support groups.

The meeting started with a brief EGM. This was held to propose changes to the Constitution in four places. The changes and their reasons had been distributed to members beforehand and were primarily to overcome the break in service after four years that was previously required. The four proposals were voted in favour by a majority show of hands.

Chris Addison then gave his talk that concerned the RPCSG and how it functions as a support group, how it was formed in 2007, developed over the years and the recent two years that were affected by the Coronavirus pandemic. Chris had previously given this talk to PCUK and support group leaders for information and to present some ideas for group activities that other support groups may want to introduce. It was a useful talk giving an account of the support and other services that the RPCSG provides and an insight into the working of the committee.

One of our strengths is the fact that many of our guest speakers have been experts in their fields on matters relating to prostate cancer and other support services.

Chris then showed some graphs of membership numbers showing a steady growth in membership up to 2017 then a marked fall in 2018. This was due to the advent of GDPR (General Data Protection Requirements) that obliged us to obtain permission from members to hold personal data. Some members did not respond for various reasons, some of whom had left the group without our knowledge.

After 2018 the rate of increase in membership slowed somewhat mainly on account of the coronavirus from 2020. However our focus is not on quantity of members but rather the quality of the support that we can offer.

Chris then listed the 12 committee members including those members holding the roles of Chairman, Treasurer and Secretary and other roles that have evolved over time. Beverley has been the medical contact ever since the formation of the group in 2017.

The social side of our activities was discussed that includes two social dinners, at Christmas and in the Summer, and expression of thanks to Richard Brown for organising monthly walks and coffee mornings.

We have held a few awareness sessions but these have been restricted due to the pandemic. We intend to have another awareness session in Broad Street in Reading on the 2nd July 2022.

Catch-up is now needed, on account of the fact that during the pandemic many men who would have visited their GP and been referred to urology departments did not do so.

Chris described the support that we offer including 1-to-1 sessions for new and existing members, an RPCSG helpline number, an email address for medical issues and online exercise sessions.

The ways that we coped during the pandemic was discussed. We adopted Zoom for both committee and group meetings and this enabled some members from other support groups to join in.

Finally Chris discussed the way that we coped with the pandemic. The effect on our meetings has been mentioned and we intend to develop our meetings into hybrid meetings whereby we meet in person in the church hall as well as being on Zoom for those members who prefer to join remotely.

There then followed some open discussion between the participants, that included how to spread awareness of the support groups, possibly via CNS groups and leaflets in appropriate places, and QR codes for URLs for our web site.

THE MARCH 2022 MEETING

The March 2022 meeting featured a talk by Mr Steve Foley who is a consultant at the RBH. He is a specialist in continence and his talk was most useful. The talk was very well attended by 38 RPCSG members and 10 people from other groups.

Mr Foley's talk was preceded by our AGM. This AGM included voting for three items – the 2021 AGM minutes, the 2022 EGM minutes, and the election of seven committee members to continue their service for a further 12 months. All of the proposals were voted in favour by a majority show of hands.

Mr Foley started his talk saying that he will talk about continence and bladder issues after prostate treatment. All treatments whether radiotherapy or surgery can upset things. In the teenage years passing water about 6 or 7 times a day is normal whilst being able to hold on before needing to go to the toilet, and not needing any night time toilet visits. Bladder issues change over time.

In younger age bladder capacity should be about one pint and the capacity reduces with age as the bladder become less elastic. It signals the brain that it wants to pass water earlier than it used to, and will not hold on for as long as it used to.

If bladder capacity reduces, say to one half or a quarter of a pint this can be managed easily. Tablets can be prescribed for small overactive bladders. If these do not work then Botox can be injected to help the bladder, treatment being every six to nine months. A risk is that the bladder is slowed down too much with the risk of infection or inability to pass water at all.

Important factors are how often one need to go, and how urgent is it, and how often one gets up in the night. Kidneys can be a source of frequent night time visits. In our younger days the kidneys produce less water at night and enable us to go through the night, but in later years the kidneys do not turn off as much, also frequent night time visits can be caused by water retention during the day that is released during the night.

Another issue is weakness of pelvic floor muscles caused by treatment. Remedies for this are available depending upon the level of weakness.

Stress incontinence is caused by things such as coughing, sneezing or walking. After surgery this incontinence recovers in up to a year and currently less than 5% of people have this problem after one year.

In the first year one should do pelvic floor exercises and visit a physiotherapist. Using one pad a day and nothing overnight is classed as mild weakness and can be treated by injections into the pelvic floor muscles. This is best for minor cases and will probably not make much difference in the case of using 2 or more pads per day.

A sling can be surgically put under the urethra to provide support. There is a risk of infection. Newer slings are adjustable in clinic. Slings are useful in the cases of about 2 to 4 pads per day. More than 4 pads per day the fitting of an AUS (artificial urinary sphincter) would be considered.

There is a failure rate of AUS of about 10% per year, due to infections, leakage or failure of the device, hence it is likely that an AUS would have to be replaced after 10 years.

Radiotherapy can cause scar tissue to the area of the prostate, and the lining of the bladder loses elasticity leading to some stress incontinence and more leakage. These side effects are delayed by some years after radiotherapy. Tenderness of the bladder can be relieved by a cream introduced into the bladder.

Many Quality Of Life surgeries have been delayed by the Covid pandemic and the waiting times are a concern.

Betmiga is a muscle relaxant and very good for treating the bladder with very few side effects but can affect blood pressure.

A member was concerned that after several years on Betmiga and an increase in the use of pads, that there is no further help available. The reply was that in this case the use of Botox would be recommended.

A member whose AUS has started to give leakage problems was advised to seek a consultation at the RBH.

Question: Are strictures the same as bladder neck stenosis? Strictures are caused by scar tissue whilst bladder neck stenosis is caused by problems where the urethra is joined to the bladder. Self catheterisation helps to prevent scar tissue from closing and has no long term adverse effects.

A member had scar tissue formation and is carrying out regular ISC (Intermittent Self Catheterisation) to deter the scar tissue from reforming and was concerned about how long he should continue doing ISC. The reply was that hopefully the scar tissue will stabilise, should do after six months.

Consultants would need figures for the quantity of urine passed during day and during the night so that a treatment can be decided. Antihistamine such as Piriton is recommended at night as it turns down reactions and can help an overactive bladder.

Type of drink affects night time toilet visits. Alcohol irritates the bladder as does the rate of consumption. Other irritants are caffeine and carbonated drinks.

Mr Foley was thanked for his very interesting talk.

RPCSG WALKS

The walk in February was the popular walk from Ramsbury that included a visit to a Roman mosaic. The weather for this walk was rather wet but enjoyable.

The March walk was from the Waterside centre to the Forbury with a return through the ruins of the Abbey and a stop for refreshments at The Fisherman's Cottage. The weather was very good.



The landmark gasometer was in the process of demolition



The 'Banksy' on the wall of Reading prison



Refreshments at The Fisherman's Cottage



The next walk will be on Tuesday 12th April and the next coffee morning will be on Tuesday 26th April. The details are being finalised and Andrew intends to send these later to all members.

COFFEE MORNINGS

The February and March coffee mornings were well attended at the Cuning Man and The Mill at Sonning. The next coffee morning is due on the 26th April and as above, Andrew will send details later.

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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 1st April 2022 will be an RPCSG Zoom meeting with the guest speaker Mr Philip Charlesworth talking about recent developments in treatments.

Tuesday 12th April 2022 will be a walk, details will be in Andrew's email.

Tuesday 26th April 2022 will be a coffee morning. Details will be in Andrew's email.