

Mid Sussex Prostate Cancer
Support Group

Newsletter

February 2022



Good morning members and guests, I hope you are fit and well, despite Covid and any treatment side effects.

This year is the tenth anniversary of our support group. I feel it timely to give a great deal of thanks to Jenny Stanger, assisted by our own Jenny Lea, for having the forethought and commitment to helping us men. The first meeting was held on 19th July 2012, and was attended by over fifty men. Are any of those original attendees still members? If so, would you please contact me by email, or phone 07919 949318, with your story and progress? We will be holding a special celebration meeting sometime this year and will give further details in due course.

Our support group has also been very fortunate to have had the help of Val Banfield over the past 8 years. She has ably put her hand to any task asked of her by the committee, as well as expertly managing the refreshments for us all.

I recently found an old leaflet in a Group folder about the Pelvic Radiation Disease Association (PRD). Some of you may also find it interesting, so here is the link:

<https://www.prda.org.uk/>

Now you may think what's that got to do with me? Well, for those of us who have had radiotherapy to the prostate and or pelvic lymph nodes, you will possibly have side effects such as urinary incontinence, bowel incontinence, radiation proctitis, to name but a few. The question is - were you told these side effects might happen to you? I recall that some of these were mentioned to me before treatment, but not all. For instance, I have lymphoedema, which wasn't highlighted to me.

It seems that there is a radiotherapy consent form for prostate cancer, produced by The Royal College of Radiologists. The form is attached. I would be interested to hear if anyone had such a form, or similarly detailed information about side effects, when considering treatment.

Thanks to Rob and Andrew our website is now fully up to date, so please have a look and tell us what you think.

You will note from earlier emails that some of us have been out walking over the winter months and, now that Spring is on its way, it would be good to meet more of you. We have lots of plans and hope for your participation.

Our face to face meeting on 24th March is going to be an informal get together, much like pre-Covid days, but at a different venue: **Haywards Heath Social Club, 6/8 Wivelsfield Rd, Haywards Heath, RH16 4EG.**

At the meeting we will have three members talking to us about their personal experiences:-

Ray, who is on Active Surveillance;

Dave will tell us about his Brachytherapy, and the importance of exercise; and

Andy, who has recently had a Retzius-Sparing Radical Prostatectomy.

There will be plenty of time to chat amongst ourselves and to compare notes. Refreshments will be provided in the normal way. If you have any friends or family who are not members, who are interested in coming along, please let either me or Jenny know. We are really looking forward to some normality!

I know that quite a number of you have now had Covid, and it seems as if the effects are quite low, and much like flu or a bad cold. However, we will make our best endeavours to keep everyone safe at our meeting. We are asking that you are vaccinated, do a lateral flow test beforehand and, if you feel unwell before, or on the day, to apologise.

You may have seen or heard of the publicity campaign that started on 17th February to raise awareness of Prostate Cancer and, for those who missed it, here is a link. Entitled 'I Lost My Dad To Prostate Cancer' <https://www.bbc.co.uk/news/health-60390084>

Our WhatsApp group now has over twenty members, and it is encouraging to see lots of participation, particularly on current situations. If you would like to join us, send me a WhatsApp message to our group support number 07919 949318.

As always, it is your group, and your committee, and if you have any thoughts, ideas and suggestions on how we can make the group better for you and future members, please do let us know.

Stay safe and well.

Brian (Chair), Jenny, Val, and Rob.
MSPCSG Committee

