

WHO ARE WE?

OXFORDSHIRE PROSTATE CANCER SUPPORT GROUP

We are a patient-led group, formed in 2011. Our main aim is to offer confidential non-medical information and support to men, their partners and families affected by prostate cancer, based on our experiences.

Why should you contact us?

- Learning that you have cancer initially is a massive shock.
- People like us who have had, or still have, prostate cancer are very aware of the huge impact of a new diagnosis and understand how it affects patients and their families.
- A lot of men are reluctant to talk about medical conditions or to seek help and support, even when faced with such a lifechanging experience. However, many men find they gain a lot of comfort, confidence and encouragement from talking to other men who are either living with or who have been cured of prostate cancer.
- Any contact with us is treated in strictest confidence and we respect people's wishes to have as much or as little contact with us as they want.
- We are happy to talk to people on the phone or face-to-face.
- Don't face prostate cancer on your own - we are all survivors, so come and join us.

MAKE CONTACT...

More than 300 men in Oxfordshire are diagnosed with Prostate Cancer every year. Are you one of them? Phone us for a chat... If you are newly diagnosed or a family member of someone newly diagnosed it can be an immensely disconcerting time... So have a chat with us - we've all been there and are in this together.

Tel: 01865 595 109

Email: secopcs@btinternet.com

EVENTS 2019:

What to expect at our meetings:

A chance to meet those who have been touched by Prostate Cancer - many have gone through treatment, many are in the midst of their treatment and some have yet to embark on their cancer treatment journey. There are partners/wives and friends, all there to chat and share their experiences, to support and to learn in a casual, informal gathering. We are delighted to have wives, partners, friends and family members join us.

No need to book in - just show up - 6.30pm for 7.00pm at Oxford Golf Club Hill Top Road, Oxford OX4 1PF - (there's plenty of parking)

9 September – Mr William French, retired butler to HM The Queen, on his working life as butler to the Royal Family and other distinguished people

14 October - Simon Lord, OPCS member who has qualified as a personal trainer worked with PCUK on development of materials and ideas, will speak on exercise for mild to moderate health conditions and cancer rehabilitation. Atif Kaudri, benefits adviser from Maggie's Centre Oxford, will also attend.

14th December - Skittles Evening. Another evening of competitive bowling with family and friends - Email davehawes@btinternet.com or call Dave to book 07773 508 024 (£10 incl. food)

BUDDING THESPIAN ARCHIE CAWTHRA...

I had the absolute pleasure of meeting a young supporter during the summer.

Archie Cawthra is the grandson of our member, Dave Thomas, and earlier this year he wrote a short play, roped his family into playing parts and they performed it in Dave's garden. There was a collection amongst the audience and they raised £30 and the attached photo shows me collecting the cheque from Archie.



Chairman Steve Tuck

Archie's play "Betsy" is (apparently) loosely based on the plot of the 1974 film Benji..... Two children give a home to a stray dog they find on the street, but have to hide it from their mother. During the night the dog disappears. Next day, whilst looking for the dog the children walk into a shop which is being robbed. The robbers kidnap the children and take them to a deserted factory...

...The dog reappears, and helps the children's mother and police track down the children, who are rescued. Unfortunately the robbers escape - so a sequel to the play is now planned! The play lasted about 10 minutes, so the dialogue was not too heavy with more emphasis on the excellent acting.

Steve Tuck

**...and a note from
Archie's grand father...**

Once again, thanks for coming to accept the cheque, and making Archie feel important - and proud. The proceeds from the sequel (which I think Archie is intending to be his family production for Christmas) will again be going to OPCS!

Cheers,

Dave

David Thomas



Chairman Steve Tuck collecting the cheque from Archie

PROSTATE CANCER - 'A COUPLES CONDITION'

In June the OPCS meeting focussed on the partners of men who have had prostate cancer. Prostate cancer is often referred to as the 'couples condition' and for good reason, all of you who are reading this newsletter will have been affected in one way or another, and the realisation that there is now a new 'normality'.

There were many discussions, prior to the meeting, as to whether our men should be present, the general view, however, was that the men should adjourn to the bar area for their own conversations, and very dutifully, with hardly any persuasion, did just that. This format gave both partners and men the opportunity to talk, perhaps more openly. Thank you to all who facilitated the groups.

We were very fortunate to have Baroness Jan Royall as one of the guest speakers. Jan spoke with passion about her experience of her late husband's cancer and her drive to ensure men and their partners are taken seriously and early diagnoses made. Jan is very keen to maintain links with OPCS.

Dr. Terri Gilleece, a Researcher from Ulster University is currently undertaking a study on the impact of prostate cancer from the partners perspective. Terri presented preliminary findings of her study, a strong theme was partners expressing feelings of guilt for thinking about themselves, and a sense of loss of who they once were. However, many also reported stronger relationships and a renewed intimacy.

If you are interested in taking part in Terri's study please contact her directly, a few from OPCS have already taken part and have spoken about the very positive experience. Research is hugely important in shaping future services and Terri's study one of the few that considers partners. Terri can be contacted via email at: tm.gilleece@ulster.ac.uk

There are numerous support services available, Maggie's, Prostate Cancer UK, MacMillan services. However if any partner would at anytime like to talk or meet up with someone from OPCS please make contact via OPCS directly. You are not on your own.

Sue Boyce, Peer Support Manager, from Prostate Cancer UK fed back preliminary findings of a survey conducted by PCUK to influence change. Mary Mountford-Lister, from the Maggie's Centre at the Churchill spoke to the group about the invaluable support Maggie's can offer.

Finally if you have any ideas yourself, or resources you would like to share that you feel could support others please make contact.

Caroline Prance



Committee member
Caroline Prance

GET INVOLVED TO HELP OTHERS...

Come and join the Oxfordshire Prostate Cancer Support Group committee. Under the chair of Steve Tuck we have a formidable team taking OPCSg into the 2020s. Already a committee of eight, we have created two more places for those who want to make a difference, give something back and play their part in helping others. Have a word with either myself or our chairman Steve Tuck.

Timon (Secretary)



WALLINGFORD CLASSIC CAR RALLY



Oxfordshire Prostate Cancer Support Group is tremendously grateful to Oxford Bus Company for letting us take the big white 'Oxfordshire Prostate Cancer Support Group' bus to the Wallingford Classic Car Rally in May. In brilliant weather the bus, by its presence, got a lot of attention for the bus company and for the support group. The event started with a procession through the town. The bus, expertly driven by Grahame, took its place in the middle of the parade and was greeted with waves and cheers as it moved along the route. One of the photos, taken from inside the bus, shows the crowds in the Market Place who cheered us along. After the parade the bus was positioned at the rally site on Kinecroft.





It was visible from all over the site, and the OPCSG volunteers who were present spent the afternoon talking to passers-by and enquirers.

The bus provided a brilliant focal point for our work in raising awareness of prostate cancer, and we had many worthwhile conversations with men and their partners about the need to get checked. I do hope that we may be able to repeat this collaboration at other events that we attend. We'll certainly approach Oxford Bus Company and Grahame (the driver) if the opportunity arises. Thanks to all at Oxford Bus Company and particularly to Grahame for giving up his day to drive the bus.

John Grundy

Is there any chance that the bus will be sent out on other routes so that it can be seen more widely throughout the city?

THEY'RE ALL LOOKING AT OUR BUS...

The OPCSG bus) is normally allocated to the 13 and X3 routes. I have just seen the OPCSG bus on route 4 to Wood Farm. I use that route myself to get into town from Wootton, so maybe I'll catch a ride again one day.

John Grundy



CASSINGTON BIKE NIGHT - 24TH JUNE

The day after the River Cruise a few OPCS members volunteered to help out at the Cassington annual bike rally as car park 'attendants'. Perhaps it was the lure of the high viz jackets and matching OPCS caps that drew these volunteers..

But seriously, what a great event! The sound of the bikes in the distance then seeing them approach Cassington main street really was a sight and sound to behold.

The weather forecast had been dire which apparently reduced usual attendance figures, however there seemed to be thousands of bikes of all shapes, sizes, age and condition (I am still referring to the bikes) The evident, and understandable, sense of pride each rider had in their bike as displayed on the village green and roads, was tangible, and a great atmosphere everywhere.

Aside from this, the OPCS volunteers managed to ensure nobody snuck into the carpark without being given a leaflet a chat about the importance of getting their own prostate checked, or to talk to and encourage their partners and/or relatives. In exchange volunteers were privileged to hear many talk of their own experience of prostate cancer and care they had received. The OPCS volunteers also wandered into the village and continued distributing leaflets and talking with people. Everyone was very generous and £541.10 was raised towards OPCS.

Thanks to all of the volunteers, it was an excellent event and a great way to open up conversations about prostate cancer in an informal setting.

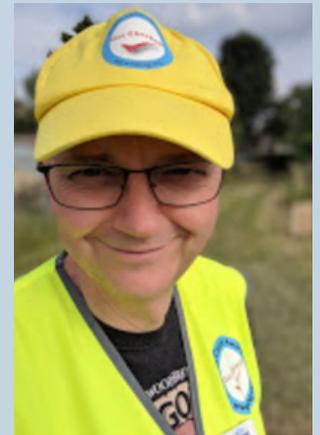
Thank you particularly to the Angela Perrin who gave us usage of the field to raise funds for OPCS as a 'thank you' to the support she and her family have received in the past.

Caroline Prance

BIKE NIGHT



Stand
and
deliver...



Have you a little space for us?

We need somewhere new to store OPCS's Banners, Leaflets and Brochures etc. About a 'small garden sheds' worth - occasional access by members of the committee would be required (on average once every couple of weeks). Have you space at work/home/in your garage - it needs to be secure, clean, dry and with relatively easy access. Or perhaps you know of a local company that would be willing to sponsor us with some space. Please let me know if you might have a solution in mind.

Timon
Secretary

Aunt Sally Event at The Ampleforth...



The Ampleforth Pub collected **£455 for OPCS**. We were presented with a cheque on the 21st August and would like to thank everyone at The Ampleforth for their support. Check out The Ampleforth in Headington - well worth a visit.

www.theampleforth.co.uk

In the picture is Dave Hawes (Treasurer) and myself from OPCS together with members of staff and customers from The Ampleforth.

Dave Beasley, President, OPCS

ANNUAL SUMMER JAZZ RIVER CRUISE

On June 23rd the annual OPCSJ Jazz River Cruise sailed from Abingdon Bridge, and what a great afternoon was had by all.

The boat was full of OPCSJ members, their partners, families and friends, about 90 in total and from start to finish – yep, no one fell into the Thames...

Along with the aforementioned, the boat was also full of chit chat, laughter, chocolates, wine, tea, coffee, music and of course the most delicious cream teas.

Mike and his jazz trio were extremely entertaining, they also played good music and got many off their benches impressing (and amazing) the rest of us with their dance moves...and this was after the 2nd or 3rd round of scones and jam and cream (or cream and jam depending on where you are from).

To conclude, the weather was really okay, not the wall to wall sun shine which the Committee had ordered, but a warm and dry event, perfectly fine.

Thank you everyone who came along, for all the volunteers, Mike et al, and most importantly, the crew..who got us 'there' and 'back' safely.

PS..If you missed the Cruise year, make sure you set a reminder to join us next year, this extremely popular event is set to continue and a predicted sell out yet again.



RIVER CRUISE FUN



IN BRIEF...

Dear Mike,

On behalf of Oxfordshire Prostate Cancer Support Group, I would like to thank you for the kind donation of £300 raised as proceeds from the John Pilkington talk in Finstock in April. This money will help to fund our work in supporting men diagnosed with prostate cancer and their families in Oxfordshire and I understand that a matching donation was made to Prostate Cancer UK, to whom we are all grateful.

Thank you for your continued support of OPCSG and PCUK.

Kindest regards,

Steve Tuck

Chair,

Oxfordshire Prostate Cancer Support Group

- **Specialist cancer massage**
- I'm writing you to offer my service in the Oxford area.
- I have my practice in Iffley Village but I also offer mobile massage for clients who amaybe too poorly to travel.
- I decided to train in cancer massage after having my own cancer diagnosis some 8 months ago.
- Thankfully, I'm now fully recovered.
- During those tough months, both physically and emotionally, massage helped me immensley. It made me feel "normal" again.
- If you would like more information please visit my web site: www.anewtherapies.co.uk/cancer-massage
- And If you have any questions please don't hesitate to contact me.
- Best wishes,
- Serena Tizzi
- 07596451697
- anewtherapies@gmail.com



IDEAS TO SHARE

We want to hear from you...

Comments on the newsletter?

Viewpoints?

Ideas for Oxfordshire Prostate Cancer Support Group?

Event suggestions?

Speakers for our meetings?

Email the secretary - we would love to hear from you.

The Secretary

Email [timoncolegrove@gmail](mailto:timoncolegrove@gmail.com)

Did you know...

- Membership of Oxfordshire Prostate Cancer Support Group is an opportunity to help others
- - one of the easiest and most enjoyable ways of doing this is to join in at the events we attend. If you haven't attended an event before, just come along and spend an hour or two with us to see what it's like - it is surprising (and unnerving) how many people/husbands/fathers/brothers/sons have been touched by Prostate Cancer - they come to speak to us at these events, people are keen to talk and find out about OPCSG and to learn that they are not alone...it's casual chatting - we listen and share...no special skills needed - just an open ear and willingness to chat...



A TOUCHY SUBJECT

"What is the biggest challenge you are facing following prostate cancer treatment?"

I wanted to make sure that A Touchy Subject (ATS) focuses on what matters most to you. There were over 100 replies to a recent survey and I've learnt so much.

I wanted to share with you three main topics that kept coming up:

1. Incontinence. Getting dry is clearly front of mind until leakage stops.

2. Erectile Dysfunction. In particular, the struggle to find options that work. Many people didn't know all their options, or what to do when something didn't work as they hoped.

But above all, the most common reply was...

3. Dealing with the great unknown. How to accept the uncertainty and frustration that post treatment life entails.

These themes will guide the next year of resources.

I've created a new Member's Area - which is free to all.

This area gives you practical resources, past webinars and recommended products all in one place.

You can access the page by visiting here: www.atouchysubject.com

By becoming a member of ATS, you will also be invited to attend future free webinars.

All the best,

Victoria, A Touchy Subject

QUESTIONS TO ASK YOUR DOCTOR OR NURSE

It's bewildering at diagnosis and hard to think of the questions to ask at the time...

If you're choosing a treatment, you might find it helpful to ask your doctor or nurse some of these questions.

- What treatments are suitable for me?
- How quickly do I need to make a decision?
- What are the advantages and disadvantages of each treatment?
- What are their side effects?
- How effective is my treatment likely to be?
- Can I see the results of treatments you've carried out?
- Is the aim to keep my prostate cancer under control, or to get rid of it completely?
- If the aim of my treatment is to get rid of the cancer, what is the risk of my cancer coming back after treatment?
- If the aim of my treatment is to keep the cancer under control, how long might it keep it under control for?
- What treatments and support are available to help manage side effects?
- Are all of the treatments available at my local hospital?
- If not, how could I have them?
- After treatment, how often will I have check-ups and what will this involve?
- How will we know if my cancer starts to grow again?
- If my treatment doesn't work, what other treatments are available?
- Can I join any clinical trials?
- If I have any questions or get any new symptoms, who should I contact?



RESEARCH STUDY PARTICIPANTS REQUIRED

Navigant Consulting, a consulting firm that specialises in product development strategy for pharmaceutical, biotech, and medical device companies, are conducting research to evaluate a novel drug for the treatment of metastatic castrate resistant prostate cancer.

Specifically, they hope to understand:-

The different aspects of the patient's care from diagnosis to treatment.

How patients view the different treatment options offered to them at this stage of disease.

What are the aspects that guide treatment choice.

Reaction to a novel treatment for prostate cancer.

They would like to speak in depth to anybody who has been diagnosed with metastatic or advanced prostate cancer or caregivers who cared for their loved ones diagnosed with this advanced stage of disease.

The interview should take about 60 minutes and they are offering an honorarium payment of £75.

If you would like to take part, please contact Rachel Blackwell at rachel.blackwell@navigant.com.