

South Warwickshire Prostate Cancer Support Group

2022 Annual Report

Our meetings and membership

Our ninth year as a local support group has seen us in a process of transition. We started the year with online meetings (January and March) and by May were back in the Shakespeare Hospice for our first hybrid meeting (8 in the Hospice and one online). The July meeting found two of us in the Hospice and 5 online! September was much the same with three of us in the Hospice and three online. The November meeting was our first in which the speaker was online and most of us (9) were in the room with 3 online.

The local meetings in Brailes, Leamington and Stratford have been particularly important this year as they allowed face2face meetings which had been very much missed in 2021 and the early part of 2022. Often these were small groups but on one occasion the Stratford group reached 8 and a similar number attended the Xmas lunch in Brailes. Having these local groups is a real strength.

In summary we have had six group support meetings this year, three of them online and three hybrids. A total of 20 men have attended our plenary meetings plus our 2 specialist nurses and Mel our link person to the Shakespeare Hospice. At least 18 people have attended a local group, 5 of whom have not been to a plenary meeting, so we have had a total of at least 25 active members this year (numbers are a bit uncertain as we don't keep records of those attending local groups. There have been four new members this year. I have had 10 approaches (telephone and/or email) about joining the group in 2022 which is a considerable increase on the previous year. Only 3 have gone on to attend a plenary group though one did attend a local group.

Issues in the Group discussions

Much of the ground covered in our discussions has been familiar: the difficulties of making treatment choices; the anxieties of a cancer diagnosis; living with embarrassing side effects of treatment such as incontinence and erectile dysfunction. But the impact of COVID on the NHS has had its knock-on effects. More people have been paying to have time to discuss treatment options with a consultant and some have opted for treatment in the private sector even when they did not have insurance for this. It is to be hoped that these pressures may reduce in the year ahead, but it is hard to be sure of that. Whatever the NHS scenario the importance of having somewhere safe to discuss options and anxieties will continue and we must do our best to keep offering this to as many men as we can.

Speakers

We noted in the last annual report that meeting online does have some benefits including greater ease in getting speakers. In January we had David James, Head of Patient Projects at Prostate Cancer Research. He described some of the ongoing

research projects they are supporting and introduced us to the concept of a Prostate Cancer Registry. PCR are recruiting to a pilot Registry, and we were encouraged to support this initiative. Our March meeting was the AGM, so we did not have a speaker. Our May meeting was our first hybrid, and it was great to be back in the Shakespeare Hospice. We did not have a speaker but Mel Clifford, our liaison person with the Hospice did provide a report on how they are gradually reopening and on some of the changes that have been made during the lockdown period. In July and September, we had no speakers and numbers in attendance were low. Our November meeting included an excellent presentation online from Mr Shah, consultant urologist at the QE in Birmingham, who provided us with two talks! In the first half he shared with us his experience as a surgeon in the British Army and in particular the challenges of being based in Camp Bastion in Afghanistan. In the second half he presented the encouraging results on the experience at the QE of moving from the old-style trans-rectal model of taking samples from the prostate to the new MRI guided approach to transperineal sampling, with its higher rate of diagnosis and lower rate of infections.

Tackle and Prostate Cancer UK (PCUK)

Nationally Tackle has been regrouping with a new committee and temporary chairman. The Articles of the association have been redrafted and the new package will be up for approval at the AGM in March 2023. I feel that Tackle is moving in the right direction and fully support these changes.

At a regional meeting on 16th May we learnt that in the West Midlands there are about 36,000 men living with Prostate Cancer. Nearly 4,000 men are newly diagnosed each year in our region. To reach out to even half of these men is a daunting challenge.

Sarah Gray from Tackle has been running the online support group for group organisers, a role that she inherited from Prostate Cancer UK. This has been much appreciated. Tackle has also produced a major new publication Knowledge Empowers which is available free to members. It is an impressive and informative piece of work.

Our relationship with PCUK this year has focussed largely on their publications. As we have started to support local PSA testing events, we have found the material produced by PCUK invaluable as an icebreaker. As PSA events can attract hundreds of men, we have distributed a lot of PCUK leaflets!

A strategy for growth

1 Supporting PSA events

We have decided to concentrate on supporting PSA events locally as our main recruitment strategy. This started opportunistically with an event at Stratford Rugby Club in March that Jill spotted in the local press. This was a great success despite all four of us volunteers contracting COVID that night! In May three of us supported the Lions PSA testing event at Balsall Common which attracted about 300 men. September saw another event at Stratford Rugby Club. All these events were clinically supported by the Graham Fulford Charitable Trust (GFCT) which also holds its own events each month at the Nelson Club in Warwick. After an approach to the GFCT, it was agreed

that we would concentrate our efforts on supporting these monthly events and review after 12 months.

2 Moving to Old Leamingtonians Rugby Club

We have been well looked after by the Hospice for many years. They also went to a lot of trouble to upgrade their meeting room during Covid so that it was equipped for online meetings. However, there were two constraints on our use of the facilities at the Hospice. One was the capacity of the meeting room that holds a maximum of 12 people. The second constraint was that the Hospice currently closes at 5 p.m. This means that we aimed to close our meetings by about 4.30 pm. Afternoon meetings are fine for most retired people, but they are not so convenient for those at work. It has also proved difficult to get speakers, particularly health professionals, to our afternoon meetings.

The move to Old Leamingtonians removes these constraints and also offers a venue nearer to the major population centre in our patch, i.e. Leamington/Warwick. It may also be that some men will find a sports club venue more familiar than the Hospice. My special thanks to Paul for suggesting this move and for making it happen.

Thanks

My particular thanks to David who has hosted the online meetings which have been essential to our continuing survival in 2022. David also looks after our website which is growing in importance every year. The committee has not met this year, but their support continues to be important to me especially in sounding out their views on new developments.

The Publicity group which ensures that invitations to join our meetings get out to as wide an audience as possible has continued to do an excellent job. In addition to posters on boards we are now on many local and specialist national websites and increasingly in GP surgeries on their digital displays. This is essential work which is invisible to everyone except those doing the work!

Thanks also to those who have organised the local groups: Peter and John in Leamington; Malcolm and Frank in Shipston, and David and myself in Stratford. I see these local groups as a key aspect of our growth and development, offering as they do the chance to talk in a meaningful way with fellow sufferers and survivors.

My special thanks go to all of you who turn up and contribute to meetings, whether online or face2face, by sharing your experiences and knowledge, offering support and advice to each other. It has not been easy to continue this in 2022 but somehow we have kept going!

Doug Badger

January 2023