

Mid Sussex Prostate Cancer Support Group

Newsletter

September 2020



Message from Mike Streeter:

I trust that over the last few months you have kept safe and been able to survive with a routine of everyday being like the previous day! With so many activities suddenly stopping I can wake up each morning trying to work out what day and month it is! It feels nothing much has changed since March; not even the weather (thank goodness) with lovely sunshine to brighten our day. In that respect we have been very lucky.

None of us could have envisaged back in November, when we last met face to face as a Support Group, that we would no longer be able to meet due to a virus that is an international pandemic. For a country to be in lockdown during peacetime is unprecedented.

As we are seeing in other countries such as Spain, France and Greece, the virus has not been conquered and it is something we are going to have to learn to live with for the near future. It is for this reason that prostate cancer support groups are having to explore new ways to support men struggling with prostate cancer.

Tackle, in conjunction with Prostate Cancer UK, have been proactive working with clinical technicians and holding regular virtual meetings with leaders of support groups. They also made available to support groups a full Zoom licence to enable them to host virtual committee and support group meetings.

I have regularly joined the fortnightly Tackle Zoom meetings, and it has been interesting getting to know other leaders and to exchange ideas. Support groups vary in size and organisation; some are charities with over 100 members and others are small and organised by just one person. It was good to find that a number of wives are actively involved in the groups.

Early on in the lockdown Tackle carried out a survey to identify what members wanted from support groups. A further survey is planned, and this will be circulated to members through the support groups. When you receive it please do complete it and return it as we need your views so that we can plan for the future.

As we are unable to meet due to government guidelines, and it is likely that the Dolphin Health Centre will not welcome us for some time yet, we held our first virtual Zoom meeting on the 23rd July when Dr Steve Allen from Reading gave a very informative and interesting talk on the changes in the treatment of prostate cancer over the last 10 years and future treatment options. This was recorded and the full video will be available on our web site within the next week. In the meantime, you will have received comprehensive notes on the presentation.

We are planning to hold further Zoom group meetings, and Talks under consideration include Incontinence, Sex and Prostate Cancer or the Side Effects of Treatment. You will continue to receive our Newsletters and we will be developing the website so that it contains more information on prostate cancer.

If you wish to discuss with members of the committee any issue regarding your treatment pathway, please don't hesitate to contact us by telephone or email. We cannot give medical advice but we can share knowledge and experience. In the meantime, continue to keep safe.

Mike Streeter

Tackle Zoom Meetings - The Road to Recovery

At the Tackle Zoom meeting on the 14th of August, Amy Rylands from Prostate Cancer UK talked about how they are working with the NHS on the road to recovery following Covid 19 to ensure the needs of prostate cancer patients are fully considered.

In the months before the March lockdown PCUK had been working with around 60 clinical technicians to improve the treatment pathway for prostate cancer patients and progress had been made on this. As a result, they were well placed to find out what was happening during the last 5 months.

It has been well documented in the press that cancer treatment came to an almost standstill during this time. Chemotherapy for metastatic prostate cancer was put on hold, and instead, the NHS approved the use of Abiraterone or Enzalutamide for the duration of the pandemic.

PCUK are monitoring the uptake, and if they feel it is not being used, they will follow it up with the NHS.

Initially all MRI scanning ceased, but after developing new procedures to protect patients from Covid, the machines were brought back into use. Biopsies carry a high risk of infection from the coronavirus and were mostly put on hold. Those that did take place were by the transperineal rather than the transrectal method as it carries a lower risk of infection.

The Primary Care Trusts are responsible for diagnosis and monitoring, and it is very much a mixed picture on how they are beginning to resume services. The picture can also vary between GP practices within a Primary Care Trust. PSA testing has resumed with patients being contacted by telephone or letter with an appointment, which usually results in a visit to a surgery devoid of receptionists, doctors and other patients.

During the lockdown there was a drastic drop in cancer referrals but these are slowly coming back. However, it would appear that referrals for prostate cancer are coming back more slowly and are currently at 20% of normal. PCUK are working with the clinical technicians to help them to determine priorities to increase the referral rate.

As prostatectomies couldn't take place during the pandemic the robotic machines were packed away to create space for Covid 19 patients. These are now being brought back into use. Due to there being so few referrals there is not a backlog of cases.

The general consensus is that there has been a marked change in the contact between patient and consultant. The new norm appears to be only one physical meeting between the patient and the consultant with all further consultations being done over the telephone. Follow up is now more likely to be with the Urologist rather than the Oncologist. It appears this is being driven by the Secretary of State for Health and his desire to maximise the use of modern technology.

One interesting topic in the follow-up discussion with members of other support groups was testosterone testing both before and after hormone treatment. As research indicates a possible link between the patient's level of testosterone and prostate cancer, it would be interesting to know to what extent testosterone testing is carried out in Sussex.

Please note the latest Tackle Leaflet for August is on our website.

Recent Changes on Committee

Peter Barton recently decided that he was ready to retire from our committee to enable him to concentrate on his other commitments with a national prostate cancer committee. He had been with our committee for almost 8 years and we will all miss him for his enthusiasm, his knowledge, and his sense of humour. We wish him good luck for the future. No doubt he will attend some of our future face to face support group meetings - once we are no longer under threat from the covid pandemic of course!

Mike Streeter who has been Chairman of the Support Group for the past 2 years, has decided it is now time to hand over the baton to **Brian Holden** who has been a member of our support group for about 4 years. Please read "Brian's Lucky Journey" which is on our website under Members' Experiences. This gives an outline of Brian's journey with prostate cancer and his positive attitude to life.

Mike will, thankfully, continue to be an active member of the committee. While we continue to be restricted to Zoom meetings, both he and Brian will attend the regular Tackle and PCUK Zoom meetings in order to keep us all updated.

The committee are very grateful to Mike for all the invaluable help and advice he has provided during his Chairmanship, and we will now look forward to working with Brian as our new Chairman.

Next Zoom Talk

We are hoping to arrange a Zoom meeting with Speaker on "Sexual Dysfunction" on a date still to be agreed in October. You will be advised of all details as soon as these are finalised.

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From Brian Holden, Mike Streeter, Jenny Lea,
Val Banfield and Brian Johnson

Please Keep Safe