



Awareness Support Information

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*a Founder Member of the Federation of
Prostate Patient Support Groups, known as 'TACKLE'*

Newsletter No. 74 - June 2020

Prostate Cancer Clinics & Surgery School During the Coronavirus Pandemic



Since commencing the Prostate Surgery School last October, I have received great positive feedback from those who have attended. The feeling of being more prepared to face and being advised how to manage the different side-effects of a radical prostatectomy have dramatically alleviated the fear of undergoing what could be a life-changing operation.

For various reasons, it was decided that the original venue for the School was unsuitable. I therefore had to search for an alternative, preferably within the hospital perimeter and, with the tremendous help of Ray Cossey and his wife Teresa, it was negotiated that the seminars could be held in the Big C Centre from April onwards. I am so grateful for the support they gave me and for the flexibility of the Big C Centre; it is so reassuring to know that a venue for our meetings is secure for the foreseeable future.

Having secured this venue, we were then hit by the Covid-19 pandemic and, inevitably, this has had a huge impact on how the hospital is run and how the care of patients is managed. Sadly, all group meetings have had to be cancelled. However, although I am unable to hold the meetings on a face-to-face basis, I do send in the post all the same information the patients would have received had they been able to attend. This is not ideal, but at least they are not missing out and are getting essential help, albeit in a different form. The pack includes my 'phone number and an invitation to have a chat if they feel the need.

The pandemic has affected the way all clinics in the hospital are run, and our prostate cancer clinics are no exception. Triaging GP referrals has not changed, although the number of referrals has reduced dramatically. MPMRIs (Multiparametric MRI scans), which are pre-biopsy scans, are still being carried out, but only for those patients where it is considered essential and who are on the two-week wait pathway. All PSA clinics are carried out by 'phone and where a patient has already had an MPMRI, or any other form of imaging, their results are being given by 'phone too. Those who it is felt cannot be accurately assessed by 'phone will still be seen face-to-face when absolutely necessary. Not many fall into this category but that option is still available.

LRRPs (Lap Robotic Radical Prostatectomy) are still being carried out for patients who have a high-grade disease. All other non-urgent cases are being offered hormone treatment and/or frequent monitoring if they are anxious about not having any treatment at all.

For the future, the production of a video of the Surgery School that patients can access in their own time is being considered, which will augment the message contained in the Information Packs. I would like to reassure all patients that I and every member of the prostate cancer team are still working to our usual very high standards during these perilous times and will continue to do everything we can to ensure everyone is treated with the utmost professionalism and urgency where necessary.

Helen Walker, BSc (Hons)
Prostate Pathway Nurse Specialist

Prostate Cancer Men Swap Chemo for Precision Drugs

It was reported on the BBC News website on 6th May that NHS England has said men with advanced prostate cancer can now take highly targeted hormone therapies at home instead of having to attend hospital for chemotherapy.

This is as a direct result of the current coronavirus pandemic as the NHS wants all urgent and essential cancer treatments to continue during this perilous time. Chemotherapy drastically affects the immune system, which would leave patients seriously exposed to the Covid-19 infection.

As well as relieving pressure on the NHS resources, the drugs are smarter and kinder treatments and could extend the lives of many more patients.

This precision-medicine approach is already used to treat other cancers. It is a huge shock to be diagnosed with prostate cancer in the first place, but then to be advised that chemotherapy is the recommended treatment must surely exacerbate the anxiety in these dangerous days. That is why this development is such great news.

Until now, the drugs were available only to patients for whom another hormone therapy had stopped working. Now, doctors can prescribe them when a patient is first diagnosed.

Enzalutamide blocks the effect of the testosterone hormone on prostate-cancer cells, preventing them from growing. Patients intolerant to this drug can be prescribed abiraterone, which stops the body producing testosterone.

Professor Nick James, of the Institute of Cancer Research, has led major trials into targeted prostate cancer drugs.

He says, *"I am pleased and relieved that many more men should benefit from targeted hormone therapies right from when they are first diagnosed. Men can take their tablets from home and have their bloods checked by their GP. Unlike chemotherapy, these drugs have no significant effects on patients' immune systems"*

National Clinical Director for Cancer, Prof. Peter Johnson, added :-

"The NHS has been working hard to ensure the safety of cancer patients during the pandemic. Switching from chemotherapy to hormone treatments for prostate cancer is just one example of how we are adapting our approach to help thousands of cancer patients across the country continue to access the care they need."

At last, some good news indeed.

Please Submit Your Story or Article of Interest

The following blank space is where we would love to see an article from you that would give our publication more of a personal and/or local interest.

*Your story could fill this space
in a future edition of this Newsletter*

I and Ray Cossey, your Newsletter Editor and Publication Designer respectively, have repeatedly requested such in previous editions and verbally at our meetings; we can only source/produce so much ourselves

Articles should be relatively short, but be relevant to prostate cancer issues. Personal stories are very timely and could include things like how your disease was first diagnosed, when, the treatment prescribed and your journey to the present day.

Has anyone attended the seminars referred to in the article on the front page, by Helen Walker; if so, was the experience beneficial and what improvements would you suggest, if any? One day, your story could be an inspiration to and lessen the anxiety of someone newly diagnosed. **Do please consider helping in this respect; it is important to relate positive experiences to the wider audience.**

Also, any fund-raising stories are very newsworthy. Professor Cooper's **PUR** and **TIGER TESTS** (see articles in previous editions and on page 3 of this Newsletter) are still in need of funding and if you could help that most worthy cause and then relate the story, it would be great.

If you would like assistance in putting something together, I am most willing to help, and if you would prefer to remain anonymous, that is OK too. Just let me know.

My e-mail address is :-
geoffreyowalker@googlemail.com

Pioneering test given £270k to help improve diagnosis of prostate cancer

(This article was originally published in the Eastern Daily Press)

Norwich scientists have been given £270,000 towards a pioneering test which could be used in the fight against a cancer that kills one man every 45 minutes.

The team at **University of East Anglia** has received the funding from 'Movember' as part of Prostate Cancer UK's research innovation skill which is investing £2.8m into eight projects across the United Kingdom. More than 11,500 men die from prostate cancer in the UK each year.

The UEA researchers have been developing a home urine test, called the PUR test, which could be used to indicate how aggressive a man's prostate cancer is and ensure they receive the right treatment.



Professor Colin Cooper, who is leading the research, said he hopes it will bring them one step closer towards a more accurate diagnosis for men everywhere. He said: "One of the biggest problems with diagnosing prostate cancer is that we currently can't say for sure which cancers are aggressive and need immediate treatment, and which will never do any harm." The test will look at genetic material secreted by prostate cancer in urine.

The team plan to recruit 450 men to pilot their test, which they hope will be able to predict how aggressive a man's cancer is without an invasive biopsy.

Researchers hope to explore if the test could be used to monitor men who have been diagnosed with a non-aggressive form of the disease.

Prof Cooper said: "That's why we're so excited about this test, which could give men and their doctors more certainty about the best course of treatment. "It could even be taken at home, so men won't need to visit the clinic, and could avoid an invasive biopsy."

Prostate cancer is the most commonly diagnosed cancer in men which mainly affects men over 50, with risks increasing with age.

Prostate Cancer UK has invested more than £11m into research over the past four years. Simon Grieveson, head of research funding at Prostate Cancer UK, said: "This research could revolutionise prostate cancer diagnosis and give men the assurance they need to choose the right treatment for them. We need to fund more research like this, which is why we're asking everyone to help support Prostate Cancer UK as we continue to fund research into better tests and treatment for men with prostate cancer."

Footnote

Our Support Group has also made a contribution towards aiding Professor Cooper and his team in their research and development of this pioneering test, albeit minute compared with the donation made by Prostate Cancer UK.

A much more substantial donation was made by the **Provincial Grand Lodge of Norfolk**, which last year donated the magnificent sum of **£191,000**. This was a huge effort by the 3,100 Norfolk masons, for which we applaud them.

For more information about prostate cancer research at the University of East Anglia visit their website at:-
www.uea.ac.uk/research/explore-uea-research/improving-prostate-cancer-diagnosis

Message From Your Editor

Due to the Covid-19 situation we find ourselves in, this edition of our Newsletter is only in electronic form, our printer still being in lock-down. Your Production Team discussed whether to produce anything at all, but we came to the not-too-difficult decision of yes, we should.

It was felt to be most important to remain in touch and to let you know about what we discern to be the latest prostate-cancer news, albeit perhaps less than usual. Included is the front-page article from Helen Walker about the recently-introduced Surgery Schools and Prostate Clinics, so that you are aware of how her team is doing their best to maintain their high standard of care within the current restrictions.

In my article requesting submissions of interest for future newsletters, I have again mentioned Prof. Cooper's project. I hope we can upload his brochure electronically for your information. I have a good supply of hard copies for those who would like one. Just let me know if you do, but I will need your address.

By now, we all understand just how important it is to stay safe. Now that we are well into this pandemic, world-wide research has revealed that approximately 30% of patients who become seriously ill develop dangerous blood-clots in their lungs. Back in March, as coronavirus was spreading across the globe, doctors started to see far higher rates of clots in patients admitted to hospital than they would normally expect. The virus has also increased cases of deep-vein thrombosis usually found in the leg.

Roopen Arya, Professor of Thrombosis and Haemostasis at King's College Hospital London, considers this to be a major problem. The virus is producing chemicals which make the blood 'sticky'.

This is leading to higher rates of strokes and heart-attacks and is contributing to high mortality rates. Current 'blood-thinners' are not always working either. There is a big push to get medical teams across the world to co-operate in finding the safest

and most effective way of tackling this problem.

There are trials to find a standard dosage of 'blood-thinners' to be used in all countries. I do not relate this topic to alarm but in the spirit to inform and to make us all aware of possible dangers. My medication includes a blood-thinner and I think the message is clear: **keep isolating and stay safe**. If we remain sensible; if we adhere to what is recommended as best practise, then I'm sure we will pull through.

Until the time we can resume our normal gatherings and meet again, I send best wishes. And please don't be afraid to contact any of us if you need clarification on any related matter. **Geoff Walker** - Editor

FUTURE MEETINGS for 2020

Free car parking

Light refreshments

Any of the remaining meetings for this year might be cancelled because of Covid-19 restrictions on public gatherings. Please visit our website for all up-to-date information
www.prostatesupport.org.uk

Saturday 11th July - Meet & Chat Meeting (11.45 am - 1.15 pm)
Louise Hamilton Centre, James Paget Hospital, Gorleston.

Monday 3rd. August - Meet & Chat Evening (7 pm - 9 pm)
'Big C Centre', Norfolk & Norwich University Hospital

Monday 7th. September - Open Meeting with Speaker (7 pm - 9 pm)
Benjamin Gooch Theatre, Norfolk & Norwich University Hospital

Sat. 17th. October - Meet & Chat Meeting (11.45 am - 1.15 pm)
Louise Hamilton Centre, James Paget Hospital, Gorleston.

Monday 2nd. November - Meet & Chat Evening (7 pm - 9 pm)
'Big C Centre', Norfolk & Norwich University Hospital

Monday 7th. December - Open Meeting with Speaker (7pm - 9pm)
Benjamin Gooch Theatre, Norfolk & Norwich University Hospital

MEET & CHAT MEETINGS - When prostate cancer patients can meet & chat to fellow patients and a specialist nurse

OUR WELFARE TEAM ARE GEORGE & JILL SIELY

who live in Happisburgh and are always available to give help and support to any member, and/or their family, who requests it. They have a contact list of fellow members of our support group and are able to put you in contact with someone who has been on the same prostate cancer treatment journey as you.

Call 01692 650617 if you would like to have a chat with either of them.

How To Contact Us

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