

Registered Charity No. 1108384 Website : www.prostatesupport.org.uk e-mail : nwpcsg@hotmail.co.uk Patron: Martin Bell O.B.E., President: David Haines

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

Newsletter No. 70 - June 2019

The 'Procedure' Couch

investigation of suspected prostate cancer. In the be in excess of £300,000. process of decision making, using MRI scans, together with an optimal prostate biopsy strategy, is key. When men with suspected prostate cancer are referred to the hospital via their GP, they may be offered a prostate biopsy; either transrectal or transperineal.

tissue being taken through the back passage under Jermy, as well as Mark Catling, Divisional Operalocal anaesthetic in outpatients. With this procedure, tional Manager for Urology for their support in setting there is a slightly higher risk of infection (due to pass- up this innovative technique at the NNUH, which will ing through stool) and, in larger prostate glands, no doubt benefit thousands of men in years to come. some parts may be inadequately sampled.

Transperineal biopsies are performed through the perineum (the skin between the scrotum and the back passage) under a general anaesthetic in theatre, where around 30 passes of a biopsy needle are made. This is the current 'Gold Standard' approach, which has a lower infection rate and better access to the prostate, whilst taking more biopsies. However, there are the potential risks of a general anaesthetic as well as making a number of punctures in the perineum. The need for a general anaesthetic and the demand for theatre space currently leaves the transperineal prostate biopsy waiting list at roughly four weeks.

A new development now allows clinicians to take prostate biopsies via the transperineal approach but under a local anaesthetic, and more importantly, in the outpatient setting. This procedure allows patients the use of a Couch, where, at the most, only four punctures are made through the skin (usually there are only two), The biopsies can be undertaken within days of a clinician seeing a man with suspected prostate cancer. Our aim is to offer a same day biopsy service to this group of men. Not only will this help to relieve anxiety, as there will be no wait to biopsy having seen a specialist clinician, but hours of theatre time will be freed up where other cancer and benign procedures can be performed.

NICE has recently introduced new guidance for the The annual saving in theatre costs is estimated to

The **Couch** was kindly purchased on behalf of the Urology Department by the Norfolk and Waveney Prostate Cancer Support Group and we offer our most sincere gratitude to them for such a wonderful gift; it enables us to deliver a unique service. In addition, we would like to thank our Prostate Cancer Transrectal prostate biopsies involve 12 cores of Specialist Nurse colleagues, Sam Grainger and Sallie

Mr Utsav Reddy (Consultant Urological Surgeon) Ms Helen Walker

(Urology Clinical Nurse Specialist for Prostate)



The Our Support Group's donated Couch, in situ within the Edgefield Ward of the Norfolk & Norwich University Hospital.

Footnote - it is anticipated that in our next issue, we will have interviews with comments from the first group of patients who have undergone this new procedure.

Geoff Walker - Editor

Prostate patients to be spared treatment with new NHS guidance

by **Ben Spencer**, Medical Correspondent of **The Daily Mail** and reproduced with their kind permission

Thousands of men with prostate cancer will be Vincent Gnanapragasam, a consultant urologist at the spared aggressive treatment thanks to landmark NHS University of Cambridge, said: 'Clinicians do not want guidance which advises a 'watch and wait' approach for those at low-risk.

Official guidelines for the first time say 'active surveillance' - in which a patient is monitored rather than treated - should be presented as an 'equal choice' alongside surgery and radiotherapy.

Doctors called the move a 'remarkable' step which would spare many men from the side effects of unnecessary treatment, such as incontinence and impotence.

The guidance, published by NHS watch- dog NICE, makes clear that radical treatment for low-risk prostate cancer makes almost no difference to life expectancy

Those who choose active surveillance should be given tests every six months and an examination every year and undergo rapid treatment if their cancer spreads.

While breast cancer treatments are increasingly tailored and personalised, prostate cancer still uses a 'one-size-fits-all' approach. The new guidance begins to close that gap.

Some 47,000 men are diagnosed with prostate cancer in the UK each year, but the severity of the disease varies hugely. Rapid treatment for men with aggressive forms of the cancer is vital and 11,800 men still die from the disease each year. But around 30,000 men have localised tumours, which have not yet left the prostate.

Many undergo radiotherapy or surgery but it is often best to offer no treatment at all. Until now, however, doctors have been afraid to offer this advice.







We now have our own Facebook page, where those affected by, or have an interest in, prostate cancer can post their messages, or they can comment on other people's.

It is the perfect platform for you to share your experiences; to publicise any of the events you are undertaking to assist the Group's fundraising and for you to keep up-to-date with our activities.

> Try it at :https://www.facebook.com/ ProstateCancerSupportNW/

Of course, we still have another presence on the internet with our website at

www.prostatesupport.org.uk

University of Cambridge, said: 'Clinicians do not want to be seen to be telling people not to have treatment." Patients, meanwhile, will often demand action when they hear the word 'cancer'.

The new NICE guidance attempts to bridge this problem by spelling out the chances of survival - and the side effects - depending on the forms of treatment.

Two in every 100 men who opt for active surveillance will die from prostate cancer in a decade, compared to one in 100 for surgery and radiotherapy. The chance of the cancer spreading is higher with active surveillance meaning some men end up having to be treated eventually.

Professor Freddie Hamdy, of the University of Oxford, who led a decade-long study into active surveillance published in 2016, said: 'It gives the patients choice and options which are based on evidence.

The moment patients hear the word cancer they want it treated, and they can pay the price of that treatment in side effects. This is quite remarkable and could really go some way to reducing the risk of overtreatment.

Prostate Cancer UK said the guidance was an 'endorsement' of active surveillance. Heather Blake, director of support at the charity, said: 'This could potentially provide thousands of men with the opportunity to safely delay or avoid radical treatment and its associated side effects.

We have reproduced this article in the interests of keeping our members informed of the latest NICE guidelines However this should not be taken as any endorsement of these new guidelines by this Support Group.

We do not give any medical advice as this is strictly not within our remit. The need to know whether a prostate cancer requires more urgent treatment totally validates Prof. Cooper's research .(See article on back page)- Editor



Our thanks to cartoonist, Adrian Raeside for allowing us to reproduce his cartoon

Our thanks, for sponsoring this edition, go to



Caught short by the boys in blue

Prostate problems and a long car journey drove comedy writer Laurence Marks into a seriously embarrassing encounter with the law

'm afraid I have some bad news,' said the consultant urologist. 'Am I going to live?' I asked. 'For many decades, I hope,' he replied. 'The bad news is you have an enormously enlarged prostate.' He showed me my MRI scan. 'You see, your prostate should be the size of a peanut, but yours is the size of a small mandarin.'

So this would account for the fact that for the past decade I had to get up as many as ten times a night to have a pee, only to find, when I reached the toilet, that nothing happened. I would stand there for ten minutes, waiting for so much as a drip, but all the time feeling that, if I didn't have an urgent leak, I would burst.

I am sure many of my fellow male *Oldie* readers know the feeling.

Living in the Gloucestershire countryside and driving in and out of London was proving a severe test. I couldn't motor for three miles without having to go in search of a toilet. When there wasn't one available, I was in trouble.

I started to compile a guide to where all men's public conveniences were situated on the A40 and M40. I could have written a book. I was asked to. A bestseller I was told, for my urologist said that millions of men over 50 suffer from prostate-related problems.

For my birthday, my wife bought me a HeWee, a sort of plastic receptacle in which you can have a pee on the move, or stuck in traffic, which was far more often the case. It was of some use, except the inside of my car started to smell like a motorway toilet.

Returning from a party in London one evening, driving casually along the A40, I was suddenly gripped with the urge to get to a toilet pretty damn quickly.

The one I usually used, opposite the Hoover Building, was out of order. I knew the next public toilet was at the Beaconsfield service station but that was a good 20 minutes away and I wasn't



sure I could make it. I popped into a Lebanese grocery store to see if they sold StayDry pants for men, but then thought, 'Even if they do, where am I going to put them on?'

I made the decision to try and make it to Beaconsfield. If only someone hadn't nicked my HeWee. Yes, really. I had left it on the roof of my car (empty) when filling up with fuel, and, when I paid my bill and returned to my car, it had gone. Who would want a secondhand HeWee?

So the dash to Beaconsfield service station began. The urge to get to a toilet was becoming imperative. It was a race against time.

I was just five miles from my destination. I put my foot down and was travelling at 105mph. Then suddenly, in my rear-view mirror, I spotted a bluelighted traffic cop car.

Should I stop? Do I race the cops to the service station loo? I opted for the latter. I continued at a steady 107mph but, just two miles from destination toilet, I was being flashed by the police car. I continued. They overtook me, blue lights flashing. Two policemen pulled me over and both got out.

'Turn off your engine and get out of your car,' they instructed.

I did so, but then went for broke. 'Look, constable...'

'I'm a sergeant. And do you know what

speed you were travelling?'

Believing my bladder would burst, I said, 'Look. I don't care what speed I was doing. I am in desperate need of a toilet. I have a prostate the size of a kumquat and, if you keep me here talking, I will have no alternative other than to pee all over your boots.'

They looked at one another. They had never heard an excuse like this before. 'Then you better go inside that bush and then we will nick you.'

So I did. Relieved, I returned to the still flashing blue light and was told I was doing 108 in a 70mph zone and that meant a prolonged driving ban.

I explained what an enlarged prostate was – neither knew – and its effects, and how it was sure to happen to them when they became oldies. Once again they looked at one another.

'And it will put paid to your sex lives.' 'It won't?' they asked.

'It will,' I assured them.

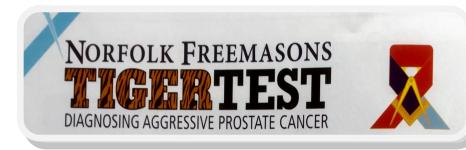
That did the trick. I could see them discussing life in 30 years' time.

'So, you going to nick me then?' I said. 'It would be such a pity as I have memorised every toilet from London to Cheltenham.'

They thought, they laughed, and then the sergeant declared, 'No, not this time. Go on, piss off.'

'If only,' I said. 👃

We acknowledge the publisher's and author's permission to reproduce this article from March 2019 edition of 'The Oldie' magazine'



They Did It And Didn't They Do Well !

You will have read in two of our editions last year about how **Norfolk Freemasons** had pledged support for Prof. Cooper's *Tiger Test* Appeal, following his pioneering breakthrough for the diagnosis of aggressive prostate cancers. Prof. Cooper had spoken about his discovery at our Group meeting held in December 2017, following which, I submitted a case to my Provincial Grand Master, Right Worshipful Stephen Norman Allen, to support this worthy cause. He took it on board and in May 2018 launched the appeal as his Charity of the Year.

The Provincial Grand Lodge of Norfolk then moved into action. The initial aim was to make a considerable contribution towards the £144,00 cost of an **Affymetrix Microarray Scanner**, a key piece of equipment needed for research and setting up of a Screening Laboratory.



RW Bro. Stephen Allen

A four-page leaflet, with the *Tiger Test* logo was professionally designed, printed, and made available to all members, their families and friends: specific Gift Aid envelopes were produced for taxpayers, to enable the recovery of tax from HMRC: over 1000 lapel badges were ordered and sold (as shown above) and all at the Province's own expense without detriment to the appeal: one member even shaved off his beard and raised £1200. In just eight months, £145,000 had been donated and banked. At the beginning, none thought, even in our wildest dreams, that such a sum could be realized so quickly.

The appeal obviously touched the hearts of many. Lodges and Chapters were still committed to add to that total, so it was decided to allow the appeal to run its intended course until 31^{st} March 2019. All amounts above those used to purchase the scanner will be allocated to assist in the speedy implementation of Prof. Cooper's trials, which are anticipated to cost in the region of £2m.

The final contribution was disclosed at the annual Provincial Grand Lodge meeting on 23rd May 2019; it amounted to £191,000! To think that the 3,100 **Norfolk Freemasons** have contributed almost 10% of Prof. Cooper's total project cost is an absolutely staggering achievement, one of which they can be justly and immensely proud, just as I am at being a member of that organisation. Our most grateful thanks go to all involved.

Geoff Walker - Editor

STOP PRESS – The United Grand Lodge of England, Freemasonry's ruling body, have made an additional donation of £100,000 towards he 'Tiger Test' project . It still requires continued funding, to ensure this development comes into clinical practice quickly, please donate whatever you can (however little) through the UEA Development Office at giving@uea.ac.uk or call 01603 592945.

Diary Dates

Open Meetings with Speaker

Monday 3rd. June

(7.00pm) Benjamin Gooch Theatre Norfolk & Norwich Hospital

Mon.2nd. September (7.00pm)

Benjamin Gooch Theatre Norfolk & Norwich Hospital

Meet & Chat' Meetings

Saturday 27th. April

(11.45 am) Louise Hamilton Centre James Paget Hospital Gorleston

Monday 13th May (7 pm)

the Big C Centre, Norfolk & Norwich University Hospital

Saturday 13th. July (11.45 am)

Louise Hamilton Centre James Paget Hospital Gorleston

Committee Meetings

Monday 8th April (AGM) (7pm) the Big C Centre Norfolk & Norwich Hospital

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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