Norfolk & Waveney

Prostate Cancer Support Group

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NEWSLETTER

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'Huge leap' in prostate cancer testing

If you were able to attend our December Open Meeting, at the N&NUH, you will know how well received was the talk by Mr Hashim Ahmed, consultant urologist at University College London Hospitals.

Mr Ahmed described, in an easy-to-understand way, how many current biopsy procedures used in the detection of prostate cancers had a great many shortcomings, in that they sometimes missed detecting the presence of a cancer and give no proper indication as to the grade of the cancer, or its precise location within the prostate.

The standard practice has traditionally been, following an elevated PSA reading, for the patient to be subjected to a biopsy procedure. There might then follow, if the possible presence of a cancer is detected, an MRI scan to confirm if there was indeed a cancer and where it was positioned within the prostate.

The preferred order now is for the MRI scan to precede the biopsy, thus saving the patient having to undergo a, possibly, unnecessary invasive biopsy procedure and the accompanying risks, including possible resultant infection.

Mr Ahmed said that he was confident that within a couple of years all hospitals will have adopted this procedure for the detection of prostate cancers.

During his illustrated talk Mr Ahmed spoke of the use of templates for the taking of numerous biopsy samples of the prostate; this being much preferable than the 10 to 12 samples taken using the conventional method, which was a decidedly hit-and-miss approach.

(Our support group is currently raising funds to help finance the use of the template technique at the N&NUH).

BBC Website - Front Page

A month after his talk to our group, Mr Ahmed found himself on the front page of the BBC website. This is how the BBC put it:-

The biggest leap in diagnosing prostate cancer "in decades" has been made using new scanning equipment, say doctors and campaigners. Using advanced MRI nearly doubles the number of aggressive tumours that are caught. And the trial on 576 men, published in the Lancet, showed more than a quarter could be spared invasive biopsies, which can lead to severe side-effects.

The NHS is already reviewing whether the scans can be introduced widely. Prostate cancer is the most common cancer in British men, and yet testing for it is far from perfect.

If men have high prostate specific antigen (PSA) levels in the blood, they go for a biopsy. Twelve needles then take random samples from the whole of the prostate. It can miss a cancer that is there, fail to spot whether it is aggressive, and cause side-effects including bleeding, serious infections and erectile dysfunction.

"Taking a random biopsy from the breast would not be accepted, but we accept that in prostate," said Dr Hashim Ahmed, a consultant and one of the researchers. Around 100,000 to 120,000 men go through this every year in the UK.



The trial, at 11 hospitals in the UK, used multi-parametric MRI on men with high PSA levels. It showed 27% of the men did not need a biopsy at all. And 93% of aggressive cancers were detected by using the MRI scan to guide the biopsy compared with just 48% when the biopsy was done at random.

Dr Ahmed, who works at University College London Hospitals, told the BBC News website: "This is a significant step-change in the way we diagnose prostate cancer.

"We have to look at the long-term survival, but in my opinion by improving the detection of important cancers that are currently missed we could see a considerable impact. "But that will need to be evaluated in future studies, and we may have to wait 10 to 15 years."

Angela Culhane, the chief executive at Prostate Cancer UK, described the current system of testing as "notoriously imperfect". She added: "This is the biggest leap forward in prostate cancer diagnosis in decades."

The study, led by the Medical Research Council Clinical Trials Unit, is already being considered by the National Institute for Health and Care Excellence. It will decide whether the NHS can afford multi-parametric MRI for prostate cancer. Each scan costs between £350 and £450 pounds per patient - so introducing them for all patients across the UK would have a bill around the £40m mark. But each biopsy costs the NHS £450 so reducing the number would deliver savings. Catching aggressive cancers earlier could also deliver savings as could not treating patients with very low-risk cancers. A full cost-effectiveness analysis is being carried out.

Prof Ros Eeles, from the Institute of Cancer Research in London, said the study was "very important" and "provides ground breaking data".

The chairman of the British Society of Urogenital Radiology, Dr Philip Haslam, said: "Today's findings represent a huge leap forward in prostate cancer diagnosis. However, the biggest issue could be the number of scanners and training people to interpret the results.

Meet the Fockers 3

'The prostate cancer screening test that saved my life'

American comedian Ben Stiller, star of the hilarious "Meet the Fockers" films, has a serious and very relevant story to tell.

He was diagnosed with cancer in 2014. "I was fortunate it was detected early enough to treat."

"So, yeah, it's cancer," my urologist said in a slightly nonplussed way, gazing at the results, "I was surprised myself."

I got diagnosed with prostate cancer on Friday, June 13, 2014. On September 17 of that year I got a test back telling me I was cancer-free. The three months in between were a crazy rollercoaster ride with which about 180,000 men a year in America can identify. [In the UK, more than 47,000 men are diagnosed with prostate cancer every year – that's 130 men every day].

As I learnt more about my disease, I was able to wrap my head around the fact that I was incredibly fortunate. Fortunate because my cancer was detected early enough to treat.

Taking the PSA test saved my life. Literally. That's why I am writing this now. There has been a lot of controversy over the test in the past few years. Articles and op-eds on whether it is safe, studies that seem to be interpreted in many different ways, and debates about whether men should take it at all. I am not offering a scientific point of view here, just a personal one, based on my experience.

I was lucky - I had a switched on doctor

The bottom line for me: I was lucky enough to have a doctor who gave me what they call a "baseline" PSA test when I was about 46. I have no history of prostate cancer in my family and I am not in the high-risk group. I had no symptoms.

What I had – and I'm healthy today because of it – was a thoughtful specialist who felt I was about the age to start checking my PSA level, and discussed it with me. If he had waited, as the American Cancer Society recommends, until I was 50, I would not have known I had a growing tumour until two years after I got treated.

If he had followed the US Preventive Services Task Force (USPSTF) guidelines, I would have never gotten tested at all, and not have known I had cancer until it was way too late to treat successfully.

'Positive' for medical tests is usually not so positive

In my case, my doctor watched my PSA tests rise for over a year and a half, testing me every six months. As the numbers continued to rise, he sent me to the urologist, who gave me a slightly invasive physical check in his office using a gloved finger. This took all of ten seconds. While I don't recommend it for fun, amazingly some don't recommend it at all. After this exam, and looking at my rising PSA numbers, he suggested an MRI to get a road map of my prostate.

It's a non-invasive procedure like the one athletes get to check for torn ACLs. Loud, but painless. Only after studying the MRI results did my doctor recommend a not-fun-at-all biopsy. Unlike the MRI, the biopsy was as invasive as it gets: long needles in sensitive places.

Then the biopsy came back positive. Of course "positive" for medical tests is usually not so positive. I had a Gleason score of 7 (3+4), which is categorised "mid-range aggressive cancer". Surgery was recommended.

At this point I sought out a few different opinions. All the doctors I talked to concurred that the tumour needed to be removed.

Ultimately, I found a wonderful surgeon who I felt comfortable with. He performed a robotic assisted laparoscopic radical prostatectomy. Due to his skill, he got all the cancer. As of this writing, I am two years cancer-free and extremely grateful.



So, what is the deal with this PSA test and why the controversy? If the PSA value is elevated, or levels rise sharply over time, it could

If the PSA value is elevated, or levels rise sharply over time, it could indicate the presence of prostate cancer. It is definitely not foolproof.

The criticism of the test is that depending on how they interpret the data, doctors can send patients for an invasive biopsy, when not needed. They can find low-risk cancers that are not life-threatening and, in some cases, men with this type of cancer get "over-treatment" like radiation or surgery, which can result in side-effects such as impotence or incontinence.

But without this PSA test itself, or any screening procedure at all, how are doctors going to detect asymptomatic cases like mine, before the cancer has spread and metastasised throughout one's body, rendering it incurable?

Or what about the men who have a history of prostate cancer in their family? Should we, as the USPSTF suggests, not screen them at all? There is growing evidence that these guidelines have led to increased cases of prostate cancers that get detected too late for the patient to survive the disease.

I think men over the age of 40 should have the opportunity to discuss the test with their doctor and learn about it, so they can have the chance to be screened. After that an informed patient can make responsible choices as to how to proceed.

I count my blessings I was given these options. After my PSA test, I went to a specialist in this field to determine the next steps. This is a complicated issue, and an evolving one. But in this imperfect world, I believe the best way to determine a course of action for the most treatable, yet deadly cancer, is to detect it early.

Some key facts for men in the UK

- There is no NHS screening programme for prostate cancer.
- You can assess your risk of developing the disease using an online tool: prostatecancer-riskcalculator.com
- All men over the age of 50 can discuss the option of having a free PSA test with their GP.
- One out of four men with a raised PSA level will have cancer. One in seven men with a normal PSA will also have it. Measuring rises in PSA levels over time is often more useful than a one-off snapshot.

David Capp

Our chairman, Noel Warner, writes:-

Last September, we went to a Celebration of the life of David Capp who, with his wife Adrienne, formed the Welfare team within the Norfolk and Waveney Prostate Cancer Group. Anyone who arrived at St Laurence's, Brundall on time or slightly late found that lovely ancient church crowded – there was standing room only.

The reason for this became clear during the service. David's life was described as full, lively and interested. His enthusiasm for work and play involved many other people and some of them described his part in their lives. His brother Bernard told of the wake up call of failing the 11 plus and his son Joe described the expeditions of the family, often on the spur of the moment.

Those of us who had only known David in the last few years found that we had missed a great deal. Born in Leicester, David spent much of his working life as Head Teacher of Brundall Primary School but this is a scant description of his involvement as he designed and implemented the culture of the school, setting it within the context of the village and encouraging Brundall people to get involved in their school. Stories of firework displays, courtesy words and weekend DIY illustrate his enthusiasm for preparing his pupils for the world beyond the school and the village.

This enthusiasm was also shown in his family life with tales of walking through different areas of the UK and his attitude towards his "leisure" hours. He appears to have considered that retirement was an opportunity to expand his range of musical accomplishment in lute playing and singing and going into new areas like sailing. Some of his activities fitted naturally together, for example the interest in lute playing and madrigals flowed into re-enactment of Tudor life at Kentwell Hall.

Surely one of the signs of a life well-lived is the huge number of people who came to acknowledge the way that David touched their lives, whether through love, friendship, service to his community or mutual interests.



Our Welfare Team - David and his wife Adrienne

David and Adrienne joined our Group as the Welfare Team some four years ago. They transformed Meet & Chat events into very positive experiences for the newly diagnosed men and their partners. David insisted that committee members and helpers spoke to someone they did not know, thus ensuring that the attendees felt part of the group. Together, David and Adrienne raised the bar for the next Welfare Team – but don't let that put you off applying!

At our recent committee meeting, Adrienne confirmed that she is only too happy to help our new Welfare Team to get started.

Shock and Awe

Man cured of prostate cancer after doctors shock tumour to death with testosterone

A man with advanced prostate cancer is believed to have been cured after doctors "shocked" his tumour to death with huge amounts of testosterone.

The result has been described as "unexpected" and "exciting" because most prostate cancer therapies work by depriving tumours of testosterone – cancer uses it as a fuel.

Other seriously ill men taking part in the same trial showed responses that astounded scientists, with tumours shrinking and the progress of their disease halted.

Levels of Prostate Specific Antogen (PSA), the blood marker used to monitor prostate cancer, also fell in the majority of the 47 participants.

One individual's PSA levels dropped to zero after three months. He shows no remaining trace of the disease after 22 cycles of treatment, and appears to be cured.

Professor Sam Denmead, from Johns Hopkins University School of Medicine in Baltimore, Maryland, who led the study, said: "Our goal is to shock the cancer cells by exposing them rapidly to very high – followed by very low – levels of testosterone in the blood. The results are unexpected and exciting".

"We are still in the early stages of figuring out how this works, and how to incorporate it into the treatment paradigm for prostate cancer. "Many of the men have stable disease that has not progressed for more than 12 months.

"I think we may have cured one man whose PSA dropped to zero after three months and has remained there now for 22 cycles. His disease has completely disappeared."

From The Daily Telegraph, 1st December 2016.

Donation by Freemasons – many thanks!



Francis of Lorraine Lodge No 6906, based in Norwich, recently held a Charity Giving Night where a total of £6,000 was donated to eleven local charities. The money was raised by the members, friends and families at lodge meetings, social events and personal donations.

One of the recipient charities was ours and the photo shows our chairman of trustees, Ray Cossey, receiving a cheque from Charity Steward Peter Leggett (left) and Worshipful Master David Clarke.

For more information on Norfolk Freemasons please visit www.norfolkfreemasons.org or like their Facebook page www.facebook.com/norfolkmasons

Reepham Rotary Club Golf Day

The venue once more will be Costessey Park and as those who have competed before will know it is a lovely course for players of all abilities, the setting is fine, the food is good and the company sublime (!)

As ever, we are raising funds for the President's charities which this year are Norfolk and Waveney Prostate Cancer Support Group, SOBS (Survivors of Bereavement by Suicide) and Norwich MIND. With your generous support, we have raised over £10,000 so far and I am sure this year will be no different.

Andrew Hadley, 01603 280873 / londiswolf@aol.com

Double-digit inflation

Jeremy Hornsby, a legend of old Fleet Street, spent New Year's Eve with a film-maker of note who has had prostate trouble.

Summoned for the dreaded probing, he saw the doctor put his glove on and suddenly felt the urge to ask him to insert two fingers instead of one.

The doctor asked him why. "I'd like a second opinion," the man replied.

Dates for your Diary

Wed 8 Mar, 5 Apr & 3 May.... 5.30-7pm
Radiotherapy Department
Open Evenings, Big C & Colney
Centre, NNUH. Meet at Big C.
Call 01603 288779 to book.

Sat 22 Apr............. 11.30am-1.30pm
"Meet & Chat" at Louise Hamilton
Centre, James Paget, Gorleston

Mon 8 May. 7-9pm "Meet & Chat" at Big C Centre, NNUH Opportunities for newly diagnosed patients to chat with members who have already been through the same journey.

DIY Radiotherapy

Prostate cancer patients at a London hospital are being prepared for treatment by finding out how radiotherapy is carried out and how it works.

They are being offered the chance to take control of the 3D radiotherapy simulator used for teaching.

Radiographer Jackie Hartigan said: "The project will help patients to see what happens during the treatment and how important it is to follow the treatment preparation instructions.

"This should help to reduce side effects and give a much better patient experience".

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- Help or Advice We have over 30 members available to help.
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