



Awareness Support Information

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

Newsletter No. 71 - September 2019

For many years this Support Group has been concerned that some GPs have refused to give patients PSA tests, for reasons best known to themselves. This article, by a now retired GP, makes for interesting reading

Looks can be deceptive

by Moss Taylor - Retired G.P.

I've often wondered how I would react if I was told that I had cancer. Now I know! I retired from general practice in 1995, at the age of 51, from what at the time was called 'burn out'. In effect it was an inability to cope due to depression, as a result of the pressures of general practice without any deputising services, so that working at week-ends and nights was unavoidable.

Back in those days, a diagnosis of prostate cancer was virtually a death sentence, as the treatment at that time was far from curative or effective in the long term. Nowadays it is a totally different story. However, I have always resisted having my PSA (prostate specific antigen) measured. That is until now. Unexplained pain in my right hip, resulted in a whole battery of blood tests, including my PSA, and thank goodness that my GP requested it, for it was significantly raised, indicating that I had indeed developed prostate cancer.

Within four weeks of having the blood test, I had had a bone scan, CT scan, colonoscopy and two appointments at the urology clinic, including a prostate biopsy, at the Norfolk & Norwich Hospital. What incredible service, and all carried out by delightful, friendly and caring nurses, radiographers and medical staff. It could not have been better if I had been a private patient. As a result of all the tests, I have now started hormone treatment, exactly a month after seeing my GP, as a precursor to having a course of curative radiotherapy.

So, back to the question I posed at the beginning. How would I react to a diagnosis of cancer? I have tried to be really positive and I believe most importantly, I have not kept my diagnosis a secret. I am perfectly happy to tell my family and friends, knowing that prostate cancer is now curable. But perhaps the most important message that I want to get across is that despite having no symptoms to suggest a prostatic problem as well as looking



perfectly healthy, the cancer had clearly been present for a while, but has been caught in time, as my scans were both normal, so looks can be deceptive. As it is slightly more common in men whose father or brother has prostate cancer, I cannot stress too strongly the importance of all men in this category, especially those over the age of 45, having their PSA measured. It is also worth pointing out that NHS guidelines to GPs state that every man of 50 or over is entitled to a blood test to measure their PSA, although obtaining one is not always easy. However, if you succeed, I can assure you, you will not regret it.

Qualifying in medicine at the Royal Free Hospital in London in 1967, Moss Taylor worked at Harold Wood Hospital, Essex as a House Physician, House Surgeon and Casualty Officer. He then moved to St Peter's Hospital, Chertsey in Surrey as a Paediatric SHO and then to Great Yarmouth, where he was SHO in Obstetrics/Gynaecology and Medicine, before completing his hospital appointments as Medical Registrar at the Norfolk & Norwich. In 1972 he became a GP, joining the medical practice in Sheringham, before retiring, on health grounds, in 1995. Since then he has kept himself busy writing nine books on birds, nearly 400 articles for the Eastern Daily Press, in the Countryside column and 500 articles for other journals and magazines. Moss has also lectured on birds, and other aspects of the countryside to various organisations in Britain, Australia and America, as well as on cruises. Moss says. "I have been so lucky to have been healthy up to now."



A New Test Called 'PUR' (Prostate Urine Risk)

Those of you who read this Newsletter regularly will recall those articles in our most recent editions concerning Prof. Cooper's 'Tiger Test'. Within this project, researchers at the UEA (led by Prof. Cooper) and the NNUH, have developed this urine test to diagnose aggressive prostate cancer and predict, up to five years earlier than standard clinical methods, whether patients will require treatment.

The experimental new test is named 'PUR' (Prostate Urine Risk). At present, doctors struggle to predict which tumours will become aggressive, making it hard to decide the most effective treatment. It is hoped this breakthrough will help large numbers of men avoid an unnecessary initial biopsy and repeated invasive follow-ups for 'low risk' patients on active surveillance.

Lead author Shea Connell from UEA's Norwich Medical School, said: *"Unfortunately, we currently lack the ability to tell which men diagnosed with prostate cancer will need radical treatment and which men will not"*. Current practice assesses a patient's disease using a PSA blood test, prostate biopsy and MRI. But, up to 75 per cent of men with a raised PSA level are negative for prostate cancer on biopsy. Meanwhile 15 per cent of patients who do not have a raised PSA are found to have prostate cancer – with a further 15 per cent of these cancers being aggressive.

A policy of 'active surveillance' has been developed as a way to combat this uncertainty, but it requires invasive follow-ups and constant reminders that a patient has a cancer with an uncertain natural history. This results in up to 50 per cent of men on active surveillance self-electing for treatment - whether they need it or not. It's clear that there's a considerable need for additional, more accurate, tests."

Dr. Jeremy Clark, a member of Prof. Cooper's team at the UEA's Norwich Medical School, added *"This research shows that our urine test could be used not*

only to diagnose prostate cancer without the need for an invasive needle biopsy but to identify a patient's level of risk. This means that we could predict whether or not prostate cancer patients already on active surveillance would require treatment. The really exciting thing is that the test predicted disease progression up to five years before it was detected by standard clinical methods.

Furthermore, the test was able to identify men that were up to eight times less likely to need treatment within five years of diagnosis. If this test was to be used in the clinic, large numbers of men could avoid an unnecessary initial biopsy and the repeated, invasive follow-up of men with low-risk disease could be drastically reduced." Georgina Hill, from Cancer Research UK, said *"the findings were promising, but needed confirming in more patients before the test could be offered routinely"*.

Further trials continue in this exciting advancement and it is most satisfying to know that we in Norfolk have played a significant role in getting the mission to this stage. The Prostate Urine Risk (PUR) test was created by using a scanning machine learning to look at gene expression in urine from samples collected from 537 men. This scanner was fully funded by donations from members of the Provincial Grand Lodge of Norfolk, and was the first step in the setting up of a screening lab to enable a clinical trials to begin.

Prof. Cooper admits that donations already received are *"...what allowed us to do it..."*. But, it is important to stress this test is not yet available; the 'Tiger Test' project still needs funding to completion. Extra clinical trials and monitoring are still required before it can be applied in a normal clinical setting, and this is why further funding is so important. For those who are able, please consider giving generously to this remarkable breakthrough in medical knowledge.

Please donate what ever you can through the UEA Development Office at - giving@uea.ac.uk or call - 01603 592945.

Found, 17 Genes That Raise Risk Of Prostate Cancer

British scientists have discovered 17 genes that radically increase the chance of carriers developing prostate cancer. It is hoped the results will help create a test to identify those at risk. Until now, scientists knew of only six genes linked to prostate cancer but this research gives a total of 23. The findings by the Institute of Cancer Research in London show men who carry any one of the mutations are, on average, three times more likely to develop prostate cancer than men who do not; some mutations give men up to a ten-fold risk. Researchers found that men with four of the newly discovered genes were, on average, 11 times more likely to have aggressive tumours than prostate cancer patients without the genes. For one of the mutations, the risk of aggressive cancer went up 70-fold. The study examined the DNA of 1,281 men with prostate cancer and 1,160 healthy men. In time, scientists believe men could routinely have a quick DNA test which would allow doctors to calculate their cancer risk. Once again though, a **word of caution**. Your team tries to keep you up to date with new developments in prostate cancer research without unduly raising expectations. It takes time for new procedures to reach the public, but to know what could be down the line in the future is exciting and encouraging. It is reassuring to understand there is so much research now in trying to combat this disease, from which deaths in men now outnumber deaths in women from breast cancer. A combination of these new trials/procedures could significantly reduce the number of those deaths. (See separate article re PUR)

Our thanks to Adrian Raeside for allowing us to reproduce this cartoon





Man uses state-of-the-art treatment to keep his hair during chemotherapy

A 70-year old man from Great Yarmouth, has used a ground-breaking scalp cooling treatment to keep his hair during chemotherapy.

Peter Kendrick, from Great Yarmouth, was diagnosed with prostate cancer in August 2017. After being told about scalp cooling, he decided to give it a go in a bid to keep his full head of hair. Mr Kendrick was treated at James Paget University Hospital (JPUH) where he wore the Paxman scalp cooling system before, during and after his chemotherapy sessions.

Although the 70-year-old did lose a few strands of hair he said it wasn't noticeable. *"My moustache thinned out significantly and I didn't have to shave it as much, which proved that without the cap I would definitely have lost my hair,"* he said. *"I would always wear the cold cap for any future chemo treatments, and I would definitely recommend it to other people who are having chemotherapy. Keeping your hair makes a huge difference to the way you feel, and the way others perceive you. You just have to persevere through the first 10 minutes, but it is totally worth it."*

The state-of-the-art technology works by lowering scalp temperature before, during and after the

administration of chemotherapy. Liquid coolant passes through the cap extracting heat from the patient's scalp, ensuring the scalp remains at an even, constant temperature to minimise hair loss.

Hair loss is a well-known side effect of many chemotherapy regimens and is rated in the top three most feared side effects for men undergoing the treatment. Cancer services lead at JPUH Angie Fenn, said: *"Our focus is on ensuring we provide our patients with the best possible care. We know that the side effects of chemotherapy, such as hair loss, can be distressing for some patients – so we are always keen to embrace any Innovation that can help reduce its impact."*

The Paxman system is available at 95pc of hospitals across the UK. It is the world-leading hair loss prevention system for chemotherapy patients and has been used by over 100,000 people in 32 countries.

(This article, by Joseph Norton, appeared in the Great Yarmouth Mercury on 12 April 2019 and is reproduced by kind permission of the publisher, Archant Community Media Limited.)



Photo is reproduced from Paxman's website



Peter lost a few strands of hair but said it isn't noticeable

A New Opportunity For Prostate Cancer Patients Choosing Radical Prostatectomy

Those of us who elected to undergo a radical prostatectomy, when we were diagnosed with prostate cancer, may recall how little information was available to us about what that process really entailed, especially if our operations were more than 10 years ago.

Speaking personally, and I do not criticise my Consultant in any way whatsoever, because that was very much the standard in 2002. It was explained to me about the operation itself, how long I would be in hospital (five days in my case – no keyhole then!) and very little beyond and nothing about how to cope with possible side effects?

I am pleased to learn, therefore, that the Prostate Cancer Nurse Specialist and a supporting Doctor propose to hold fortnightly information seminars, on a Wednesday, beginning as soon as late September, for patients who have elected to be treated by a radical prostatectomy.

The seminars will be held off-site and a venue has already been acquired. The talks will cover, inter alia, such things as:-

- * *pre-op procedures*
- * *the operation itself*
- * *recovery time/procedure*
- * *ward personnel*
- * *hospital stay/discharge*
- * *catheters – reason for and for how long*
- * *aftercare – what to expect, what is available*
- * *how to combat incontinence/impotence and much more*

I will be able to tell you about this new venture in the next issue.

It is hoped that men who have recently been treated via a radical prostatectomy might be persuaded to give some time to attending the meetings to relate their own experiences.

Please contact the Editor, Geoff Walker, if you are willing.

Diary Dates

Open Meetings with Speaker

Mon. 2nd. September
(7.00pm)
Benjamin Gooch Theatre
Norfolk & Norwich Hospital

Mon. 2nd. December
(7.00pm)
Benjamin Gooch Theatre
Norfolk & Norwich Hospital

Meet & Chat' Meetings

Sat. 19th. October
(11.45 am)
Louise Hamilton Centre
James Paget Hospital
Gorleston

Mon. 4th. November
(7 pm)
the Big C Centre,
Norfolk & Norwich
University Hospital

Committee Meetings

Monday 7th. October
(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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