

Tests that are giving men false hopes

An alarming statistic from research carried out by the Cancer Research UK Cambridge Institute: up to 50 per cent of men diagnosed with prostate cancer are being given false hopes by tests that under-estimate the severity of the disease.

They are told that they have only a slow-growing cancer but turn out to have more aggressive tumours. As a result, thousands of men are wrongly refusing treatment because they are having to make a decision without accurate diagnosis. The Cambridge scientists compared the staging and grading of more than 800 patients

before and after they had surgery. They found that, out of 415 patients whose cancer had been classified as slow-growing and confined to the prostate and would have been offered "active surveillance", 209 were found to have a more aggressive disease. In almost a third of cases cancers which had been thought to be "local" had spread beyond the prostate gland.

Mr Greg Shaw, urological surgeon at the Cambridge institute, said: "This highlights the urgent need for better tests to define how aggressive a cancer is from the outset, building on diagnostic tests like MRI scans

and new biopsy techniques which help to more accurately define the extent of the cancer. We could then counsel patients with more certainty whether the prostate cancer identified is suitable for active surveillance or not."

- *The odds of prostate cancer recurring vary with a man's blood group, according to a Tokyo University study. The disease is 35% less likely to come back after surgery in men with blood group O, the most common in Britain, compared with those in group A.*

Do not despair urges Dr Tom

Dr Tom Stuttaford, who through his column in The Times championed the cause of universal PSA testing, has clearly not given up campaigning, even at the age of 82, as we discovered when he spoke to us at our April meeting.

Dr Stuttaford, a former Norwich GP and MP and long-term prostate cancer patient, told us that he persuaded his then editor, Peter Stothard, to let him write regularly about prostate cancer which at the time received very little publicity. The campaign brought about a ten-fold increase in the money spent on prostate research – in 1987 it was a minute £30,000 a year – but the Government was not happy.

He disclosed that he was threatened that his medical and journalistic career would be finished if he continued campaigning. He was told that if all those people with prostate cancer were treated the NHS would go broke. The Government could not afford it.

"But I continued my campaign for PSA and early diagnosis," he said. "PSA is now accepted but there is a strong body of opinion that screening should be carried out only for those with risk factors, such as a family history. But that would result in a large number of people who would be left untreated although their PSA was rising."

Dr Stuttaford said that there was a mass survey underway to determine the outcome if testing was carried out only for those who were thought to be at risk. "But every man should have a PSA test and an MRI scan if the PSA is raised."

He outlined the growing number of treatments now available and said: "There are many more things coming along. Don't despair."

But looming large was "the bottom line". Posing the question, "Are we neglecting our old veterans?" he said the Treasury ran the NHS and the Treasury did not care for old people.

"They like people who die when they are 61 or 62 because they do not become a burden on the taxpayer. The position of the Treasury is that we are a liability. We don't pay vast sums in tax any more. We are just a nuisance."



Dr Thomas Stuttaford (right) with chairman Noel Warner and Daniel Williams, chief executive of BigC who took the chair for the meeting. And it's a small world – Daniel's grandfather taught the young Tom when he was a pupil at Gresham's School.

Stop press

Men with advanced prostate cancer that has spread to other parts of the body should now have access to Enzalutamide. In its final draft guidance issued on May 9, NICE has reversed its earlier recommendation that the drug should not be available to men who have already had Abiraterone. It will still be available only to men who have had a course of the chemotherapy drug Docetaxel. The manufacturers Astellas Pharma have agreed to a discount on the £25,000 cost. At present patients can receive the drug via the NHS Cancer Drugs Fund. Once the guidance is endorsed, the drug should be routinely available.

More about this in our next issue.

A tragic end to a holiday of a lifetime

Newsletter editor David Paull writes: Only a few months ago I had the great pleasure of meeting Richard Palmer and his wife Jo at the N&N's Weybourne unit where Richard and I were receiving treatment. I told them about our group, they signed up, and straight away became active members. Sadly, it was not to last. Richard, who had seemed to be making excellent progress, died on April 12 at the age of 63. Learning from a doctor at your local hospital that you have prostate cancer is bad enough. For Richard it was rather more dramatic and I invited him to tell us his story. Jo has agreed that we should still do so, as a form of tribute to "a wonderful man". This is what Richard wrote:

2012 was our 30th wedding anniversary and Jo and I decided to go on the holiday of a lifetime. Jo had spent some time in India when she was younger and I had never been. So we decided to take a railway journey through Rajasthan from Delhi to Mumbai in November. Our flight took us from London Heathrow to Delhi. The first two days were spent exploring Delhi, then we set off on our railway journey through Rajasthan and seeing sights such as the Taj Mahal, Pink Fort and Amber Fort.

Not many days into the journey I started to feel unwell. I became very short of breath and I bruised and bled very easily. I was persuaded to see a doctor in Udaipur. He took blood tests and I was found to be acutely anaemic. I was admitted to a small hospital in Udaipur for further tests, then flown by air ambulance to a much bigger state-of-the-art hospital in Delhi. Here I had extensive tests and prostate cancer cells were found in my bone marrow. I had advanced prostate cancer. My oncologist spoke to the N&N and they decided to start my hormone treatment in India. I also had several units of blood to try to build up my haemoglobin. When I was deemed well enough I was flown back by air ambulance to Norwich and spent two weeks in the N&N, being discharged just before Christmas. I responded well to treatment.

If this was not enough Jo was admitted to the N&N with acute pain in her hip and diagnosed with sarcoma in her pelvis on January 19 last year. The only cure for this was hindquarter amputation. This was done on March 11 at the Royal National orthopaedic hospital, Stanmore. Fortunately I was feeling well during this time, so I was able to visit her every day.

All went well with me until August when I got high calcium levels in my blood following radiotherapy, which made me very ill. I was offered chemotherapy which made me feel a lot better for four months. My oncologist then offered me the new drug Enzalutamide and I am a month into that. So we shall see how that goes.

Just to complicate matters I was treated as an emergency on Valentine's Night with a perforated colon and peritonitis. I had major abdominal surgery and a stoma bag fitted, so I now have to recover from that!

Jo is doing extremely well with rehab. She is walking on crutches and is starting to drive in an adapted car.

- Richard died the day before his son James was due to run the London Marathon in aid of cancer research. He has deferred his run until next year in memory of his dad.

From where I sit – the Chairman's view

As I start my third year as your chairman I want to make a determined effort to ensure that we get our priorities right for our existing and potential members.

Existing members

Those who have been diagnosed and treated have access to our web site, receive our bi-monthly newsletter, can come to Open Meetings and listen to chosen speakers, and we have funded books and fitness material for them. They know where we are and can come and go as they please.

Newly diagnosed men

In Nelson's County around 1000 men are diagnosed each year. Clearly the majority are based around Norwich but 20% are diagnosed at the QEH Kings Lynn or James Paget UH Gorleston. In April we held our first "Meet & Chat" at the Louise Hamilton Centre in the grounds of the JPUH. Our nursing colleagues did a splendid job notifying men who had been diagnosed in

the previous few months – as a result some 40 men and their partners turned up. One of the men who attended is a doctor who came because he had many unanswered questions and was able to sit with urology nurse Angie Fenn. He e-mailed me to say that he now had the answers he was seeking. The staff at the Louise Hamilton Centre were very welcoming and kept us refreshed with hot and cold drinks. We have already planned the next event to be held there for Saturday, August 9.

Those men who are blissfully unaware

The sad fact is that despite regular items in the press, and a major advertising campaign by Prostate Cancer UK so many men are not facing this possible risk to their health – and the impact upon their loved ones. When I became chairman the updated banner we produced for display at public events stated that **36,000 men were diagnosed with prostate cancer annually, and 10,000 men died of it.**

While there was some encouraging news in the press recently saying that from the 1970s to 2011 there has been a 59% increase in the 10-year survival rate for prostate cancer sufferers, the number diagnosed has now **increased to 41,000 per annum and 11,000 dying from it.**

So it must be a continuing priority for us to raise awareness – and pester men in whatever way possible – to have their PSA tested **EARLY**. This point was reinforced by the chief executive of Cancer Research UK, Harpal Kumar, when he said that early diagnosis is a factor behind the improved survival rates.

Yes, I know that the PSA test is considered to be unreliable, and attracts criticism from both sides – it can miss cancer cells entirely or can show a false picture and lead to unwanted invasive surgery – but it is still all we have got to try and detect this horrid disease.

Noel Warner, Chairman

Yvonne Haines – An Appreciation

It is with great sadness that we report the death in April of Yvonne, the wife of our founder-chairman and president, David Haines.

While setting up the group, and during his four years as chairman, David devoted a very great deal of his time and energies to leading this patient-support group: firstly bringing it into being and then guiding it through its formative years. David acknowledges that he could only have done all this with the help and unstinting support of his wife. For that our group owes Yvonne a debt of gratitude.

David Haines writes:

During my time as NWPCSG chairman, Yvonne was involved with supporting many people, visiting them in hospital and at home, and entertaining their wives at our home, during and after the period when they were losing their husbands.

I did not realise until I received their letters how much it meant to them. Yvonne is remembered for her kindness, personality and care for others; and the contributions she made quietly in so many ways.

Yvonne was born in 1933 in Horningtoft, Norfolk. She was brought up mainly by her grandparents, whom she adored. She attended Whissonsett School until moving to Harrow after the war, and later to Peterborough, to rejoin her parents when her father left the army.

Yvonne had a very independent and adventurous spirit, and at 17 left home to share a flat with a girl friend in Holland Park. During the next nine years she worked as an assistant to Jack Hylton (theatrical agent), and later with Chesney Allen (Flanagan & Allen), in a PA role. She knew many stage and screen personalities of the day, among them Jean Simmons, Arthur Askey and Richard Murdoch.

On her first marriage in 1959, she emigrated to Canada, where she spent nine years in Toronto, and where her son Justin and daughter Rachel were born. The family moved to California in 1968, with Yvonne



driving alone with her two young children across Canada and the USA from Toronto to Los Angeles, an epic feat.

She adapted to work in many different roles, including as a receptionist at the Beverly Wilshire Hotel, where she met many of the stars of the day. She was also a volunteer teachers' assistant in Santa Monica, for which she received a commendation, and even studied art and sculpture at UCLA.

In 1979 she returned to England, following a family breakdown, and after her mother's death she decided to return to her native Norfolk. She and Rachel moved to Beetley, and Yvonne found work as a lithographer at RJ Seaman's Grain Merchants of North Elmham, where she worked until her retirement.

In 1983, she met David, a widowed aeronautical engineer, who could share many of her experiences, having himself worked in Canada, the US and elsewhere. They hit it off immediately, fell in love, and were married in 1985, moving to Cheviot House (the old dairy house in North Elmham).

Yvonne was active in many aspects of village life, as a volunteer in the Meals on Wheels service and as Chairlady of

Elmham Wives Club. In 1993, they moved a short distance to Brisley, near her birthplace, realising Yvonne's dream of a 200 year old country cottage. Again, both were very active for many years in the life of the village, with a wide circle of friends.

In 2001, Yvonne was overjoyed with the birth of two sets of twin grandchildren, within weeks of each other – but being aware of impending ill-health, the couple moved later that year to Easton, for easier access to the hospital as both developed cancer at the same time. With their positive attitudes and mutual support for each other, and the skill of the staff at the NNUH, they survived, and promptly devoted much of their time to voluntary work with local cancer charities.

In 2010, Yvonne began to show symptoms of Alzheimers, which she refused to let affect her life, continuing as before until the physical effects began to take their toll, and curtail her activity. She had an indomitable spirit and met any problem in life as a challenge to be overcome – “Bubbles” by her childhood name, and “Bubbles” by nature. She had a lifelong love of the countryside and all animals. To the end of her life she always thought of others who were less well off, and was always ready to help.

In the past year or so, Yvonne was unable to leave the house, but enjoyed chatting to visitors, which always left her with a smile. Her smile and laughter were infectious, and lifted everyone's spirits.

Yvonne had a sparkling personality and a wonderful sense of fun. She will be greatly missed by her family, friends and all who knew her.

■ *A thanksgiving service to celebrate Yvonne's life will be held at St Mary's Church, North Elmham, on Monday 19th May at 2.30pm following a private family cremation earlier in the day.*

A gathering afterwards, with refreshments, will be held in the North Elmham Village Hall.

Radium ruling “a blow”

A prostate cancer test has been developed that could avoid unnecessary treatment by predicting whether a tumour will be aggressive or slow-growing. The Polaris test, developed by Professor Jack Cuzick, of Queen Mary University, London, and other Cancer Research UK scientists, measures the activity of a set of “cell cycle genes” which help drive the division of cells in the body.

After performing the test on a tumour biopsy, the cancer can be given a cell cycle progression score based on how active its genes

are. A higher score suggests that the tumour may grow more rapidly and patients would benefit from early treatment while a lower score means that patients can be placed on “active surveillance”.

Professor Cuzick said: “Overtreatment of prostate cancer is a serious issue, so it's essential that we have an accurate way of spotting those cancers that pose an immediate risk. For patients with slow-growing tumours, it's far safer and kinder to watch and wait – only acting if the situation starts to change.”

Open Garden

Bishop of Norwich's Garden, Bishopgate, NR3 1SB

Sunday 22 June 2014

Open 1-5pm £3 adults / children free



- 4 acres of landscaped gardens
- Refreshments and cakes on sale
- Raffle, children's quiz and plant sale
- Live madrigal music performance from Creakes Choral Group

Public Car Parking available near Wig & Pen, Bishopgate (NR3 1RZ) & Magdalen Street (NR3 1TA).



Money raised will go to the
**TARGETED
RADIOTHERAPY
APPEAL**
Building Money for World Class Cancer Killers



Dates for your Diary

Mon 19 May. 2.30pm
Thanksgiving Service for Yvonne Haines

Mon 2 June. 7-9pm
Open Meeting at Benjamin Gooch Theatre, NNUH

Professor Robert Thomas

Specialist in cancer lifestyle research; awarded "Hospital Doctor of the Year" and "Oncologist of the Year" titles.

'Lifestyle and Self Help Strategies after Prostate Cancer – a Review of the Evidence'

Wed 4 June & 2 July. 5.30-7pm
Radiotherapy Department

Open Evenings, Big C & Colney Centre, NNUH. Meet at Big C.

Call 01603 288779 to book.

Sat 9 Aug 11am-1pm

"Meet & Chat" at Louise Hamilton Centre, James Paget Hospital, Gorleston-on-Sea NR31 6LA

An opportunity for newly diagnosed patients to chat with members who have already been through the same journey

He is now!

After more than 50 years in journalism, your editor should know better than to write a headline, "Not yet, he isn't", on the story of Tony Benn's struggle to obtain travel insurance which led him to the conclusion that "by means of market forces, I am legally almost dead". With impeccable timing, he died on the morning the newsletter was delivered from the printer.

Stop the spam calls

Fed up with those infuriating unsolicited sales and marketing phone calls – especially the ones where the caller assures you he or she is not trying to sell you anything? There's an opt-out register – the Telephone Preference Service (TPS) – where you can record your wish not to receive them. Organisations can not legally call TPS-registered numbers. To register free, visit www.tpsonline.org.uk or phone 0845 070 0707. It won't stop all the calls but it should reduce them.

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Help or Advice – Our Welfare Team:

We have over 30 members available to help.

There is probably one near you.

For more information please call our Welfare Team, David and Adrienne Capp, on 01603 712601

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