The Royal Wolverhampton Hospitals NHS
NHS Trust

Wolverhampton Prostate Cancer Support Group

Newsletter December 2009

Welcome to the latest newsletter for the Wolverhampton Prostate Cancer Support Group. Meetings will continue for 2010 at the regular time of 1.30pm to 3.30pm at the Community Centre, Marsh Lane, Wolverhampton. Thank you to everyone who continues to support the group and attends the meetings. Please continue to contribute to the raffles, we rely on monies raised to fund the meetings.

New Programme for 2010

Here is the new programme for the next year's meetings. If there are any subjects of particular interest to you that do not appear on the programme then please let Clare Waymont or Alan Morris know.

Monday 25th January 2010 –RAFFLE
Group meeting, discussion and sharing experiences

Monday 15th March 2010
Hormone Therapy
(Ms Clyne, Consultant Urologist)

Monday 26th April 2010 - RAFFLE
Beyond Laparoscopic Surgery
(Mr Cooke, Consultant Urologist)

Monday 14th June 2010
A Pathologists Perspective on Prostate Cancer
(Dr Karnik, Consultant Histopathologist)

Monday 2nd August 2010 – RAFFLE
Benefits Advice & The Macmillan Cancer Centre
(Welfare Rights Officer – Wolverhampton City Council & Linda Hewkin)

Monday 13th September 2010
Prostate Cancer Management
(Mr Waymont, Consultant Urologist)

Monday 1st November 2010 - – RAFFLE
Radiotherapy and Brachytherapy
(Richard Gledhill, Prostate Cancer CNS)

Monday 13th December 2010
Diet and Prostate Cancer
(Speaker to be confirmed)

The Prostate Cancer Charity comments on new research into the effects of the parathyroid hormone on PSA levels

10 November 2009 (Prostate Cancer Charity Website)
The Prostate Cancer Charity comments on a new study published today (Monday 9 November) by Wake Forest University which suggests that an elevated PSA reading maybe caused by parathyroid hormone, which occurs naturally in the body.

The Prostate Cancer Charity's Head of Research Management, Dr Helen Rippon, explains: "Whilst being the best test currently available, the PSA blood test is not able to detect cancer specifically, only that there may be a problem with the prostate. The major concern with PSA testing is that while it may be an early detector for some men of an aggressive cancer, for others with the slow-growing form of the disease it may simply lead to anxiety, over-diagnosis and over-treatment.

"The levels of PSA in a man's body can fluctuate naturally over time for reasons other than prostate activity. By understanding more about other factors which may cause a rise in PSA it might be possible to spare some men who have an elevated PSA the invasive procedure of a biopsy, by ruling out other factors first.

"This study looked at the relationship between PSA level and the level of a naturally occurring hormone found in the blood, parathyroid hormone (PTH), in men who did not have prostate cancer. The results indicate that men with higher levels of PTH tend to have a higher PSA and the researchers speculate that, in some cases, it might be possible to attribute a raised PSA to higher levels of PTH alone. If true, this understanding could help refine the interpretation of PSA test results and reduce the number of unnecessary biopsies performed.

"However, we would caution against over-interpreting these findings. Correlation is not the same as causation. It is too early to say yet what the cause-and-effect relationship between PSA and PTH is – and it is also possible that a third, as yet unrecognised factor, might be regulating the levels of both. While there is some evidence to suggest PTH might directly contribute to raised PSA levels, further studies will be necessary to confirm this.

"The identification of an improved diagnostic marker specific to prostate cancer and – most importantly – able to identify aggressive tumours is perhaps the most important of all the priority areas for prostate cancer research. This would pave the way for a robust screening programme, reduce over-diagnosis and over-treatment and would make the call to action to men much more powerful and straightforward," she added.

Wedding Bells & New Team Member

We have had two weddings this year within the Nurse Practitioner team. Jenny Gould married in New York in May and is now Jenny Akins. Clare Peterson married in October and is now Clare Waymont.
Most of you will already know Helen Heap, who has been working with Clare and Jenny for a few hours per week for some time. In October, Helen was successful in being appointed as the new nurse practitioner and joins the team working four days per week.

The Prostate Cancer Charity comments on the launch of a new guide to screening

The Prostate Cancer Charity comments on the launch of a new guide, Making Sense of Screening, by Sense About Science today (3 November), which aims to explain how the screening process works, and why it is not suitable for all diseases.
John Neate, Chief Executive, said: "We welcome the launch of this new report, which attempts to explain some of the limitations of screening for a number of diseases, including prostate cancer.

"Although recent research has found that screening for prostate cancer using the PSA test could reduce the number of deaths from the disease, there are still a number of questions regarding the reliability of the test, which means that this potential reduction in the mortality rate could be at the expense of the over diagnosis and treatment of non-aggressive forms of the disease. It is precisely because of this problem of over diagnosis of indolent prostate cancers that the test is not currently suitable to form the basis of a screening programme in the UK and we commend this guide for helping to explain some of the complex issues surrounding prostate cancer screening.

"The UK National Screening Committee is currently conducting a comprehensive review of whether the PSA test could usefully form the basis of a screening programme and we await the results eagerly.

"In the meantime, we need to accept that the PSA test is far from perfect, but it is the best tool currently available that can indicate a problem with the prostate It is vital that we move as rapidly as possible to a position of 'universal informed choice', where all men are aware of the issues surrounding the test, are fully advised on its pros and cons and are able to decide whether having it is right for them."

New Cross Urology Cancer Service Questionnaire 2009

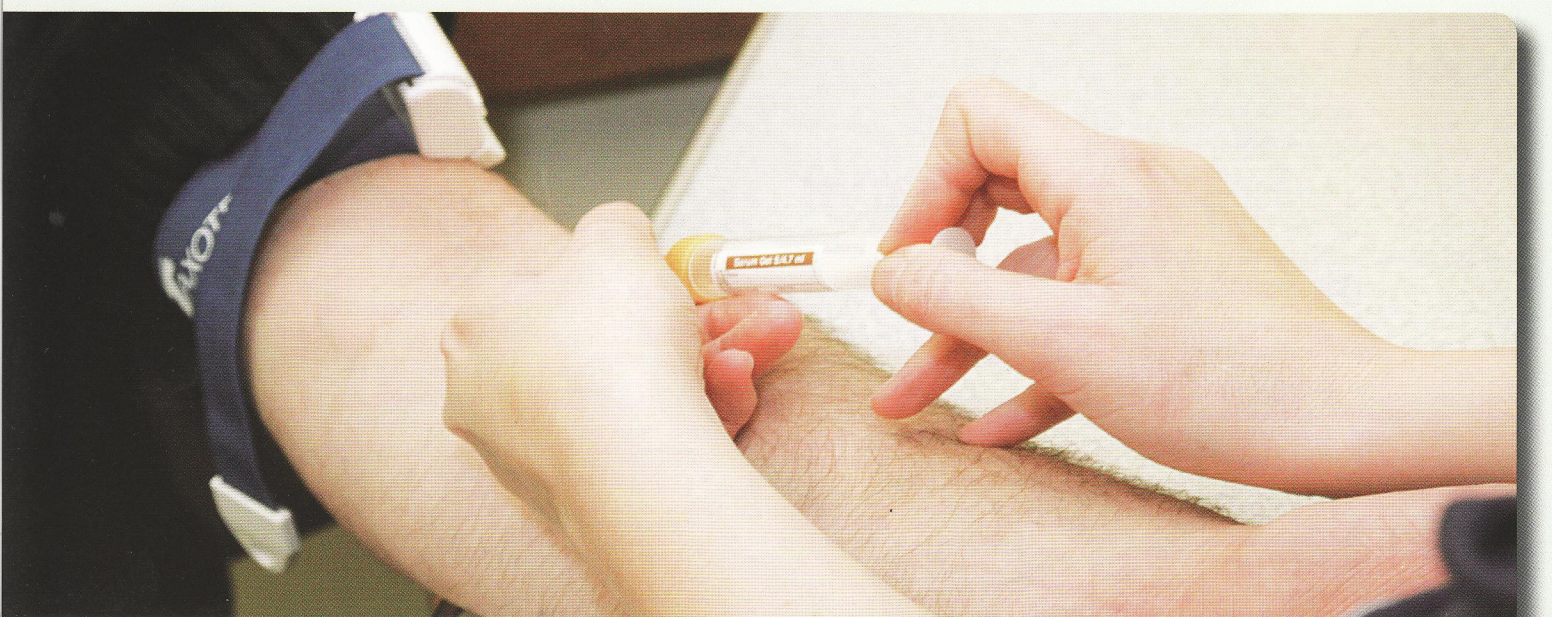
This questionnaire was sent to 40 patients with all urological cancers, not just prostate cancer, diagnosed in 2009. The intent of such satisfaction surveys is to generate comments and gain insight into the experiences of our patients and how they view the service we provide. Such comments can enable us to change or improve practice to provide high quality care.
25 patients returned the questionnaire, 84% (n=21) male patients and 16% (n=4) not specifying sex. Patients surveyed had received out patient and in patient treatment and investigations. Patients were asked to respond on a scale of strongly agree, agree, disagree, strongly disagree and not applicable.

Conclusions

Questionnaires often do not allow for any in depth information to be obtained but from the results received one of the biggest frustrations for patients appears to be not being seen on time for their clinic appointment and not being informed of clinic time delays. 8% of patients were not informed about how to access counselling and 12% felt they did not receive information about support groups. 12% of patients did not receive arrangements for their next appointment or investigations before they left the department.
100% of patients felt that the consultant or nurse had introduced themselves and explained the reasons for referral.
100% of patients felt the information they received was clear and easy to understand and 100% also agreed that the diagnosis and treatment options were discussed and a plan agreed with the patient.
88% of patients reported that they were offered a summary or copy of their discussion with the doctor about diagnosis and treatment options, despite this not being our current practice.

Recommendations

- Out patient nurses to keep patients informed regularly of clinic delays.
- All cancer patients to be offered counselling if required by consultant staff of nurse practitioners.
- All prostate cancer patients receive information about the Wolverhampton Support Group, but there currently are no other support groups for other cancer sites. There are plans to develop a support group for bladder cancer patients in 2010.
- All patients to be offered a summary or copy of their consultation about diagnosis and treatment options.



Royal Award Success for Urology

Thank you to everyone who took the time to vote for Clare and the Urology team in this year's Royal Awards. The urology team are very proud to have won this award and to have this recognition from the public makes it that extra bit special. Congratulations also to the urology secretaries who were highly commended for most improved team.

New Developments For the Macmillan Support and Information Centre

The Macmillan Support and Information Centre is looking forward to having a full time Benefits Advisor and a Support Worker post funded by Macmillan Cancer Support and Wolverhampton City Council. Linda Hewkin hopes that the posts will be advertised in January with a full time finance and benefits advice service starting in March 2010. This will make a huge difference to all cancer patients in Wolverhampton.

It will also make a huge difference to the Macmillan Support and Information Centre too. The Centre, Linda and the volunteers will be able to promote the information and support side of the Centre to patients and carers. Linda is hoping to start by providing an information table on Tuesday and Wednesday afternoons in the Deanesly Centre, providing any information that patients want, such as booklets on fatigue for those having chemotherapy and feeling tired etc.

The Greater Midlands Cancer Network also has a similar idea and Macmillan Cancer Support is also in talks with Wolverhampton Central Library about funding a part time post for provision of cancer information in the libraries. This is very topical as general public knowledge of the signs and symptoms of cancer needs extra support. The post will be part of the Macmillan Support and Information Centre.

The Aromatherapy service now becomes the Complementary Therapy service as we see the addition of Reiki added as a therapy open to all cancer patients alongside Aromatherapy. Reiki is an ancient Japanese energy-based complementary therapy. The therapist transfers energy by gently touching the patient or holding their hands just above the patient. It helps with relaxation, insomnia, well being, nausea, pain and depression. Ask your specialist nurse to refer you.

The Cancer Psychology Service is now up and running with Dr Yvonne Lewis, Consultant Clinical Psychologist leading the service and Pam Speed, Counsellor, working part time. The Macmillan Support and Information Centre is one of the venues used for counselling sessions. Ask your specialist nurse to refer you if you feel you would benefit from some counselling.
The Macmillan Support Centre and Kerry Roden the Lung Advanced Specialist Nurse have set up MALCOLM (Mesothelioma and Lung Cancer Offered Local Meetings) which has been running for nearly six months now. The Centre is also in the process of helping Dawn Dawson the Head and Neck Specialist Nurse to set up a similar support group in their area too.
Finally, if there is anything that you can think of that you would like in the support area, just let Linda Hewkin, Clare Waymont or Jenny Akins know and we can start to look at how we would support new ideas.

Behind the scenes

All your cancer care and treatment planning is required to be discussed by the urology multidisciplinary team, not just by your individual consultant. The team meets every Friday afternoon to discuss all new cancer cases and reviews any scans or results. All your urologists are members of the team, along with the nurse practitioners. The radiologists, oncologists and pathologists are also present each week. Most of you will never meet a lot of the team but each person's role is very important. We are very lucky to have Dr Karnik and Dr Fuggle as our pathologists and they give the team information about the type and aggressiveness of cancers which then allows the team to decide on a treatment plan. This treatment plan can then be discussed with you by your Consultant. Dr Karnik has been a pathologist at New Cross since 2002 and Dr Fuggle has worked within the Trust since 2000.

Prostate Cancer FAQs

(Everyman - UK's Leading Prostate and Testicular Cancer Campaign)

How common is prostate cancer?

More than 35,000 men in the UK are diagnosed with prostate cancer each year. It has overtaken lung cancer to become the most common cancer in men. With PSA testing on the increase and an ageing population, incidence is predicted to rise ahead of breast cancer during the next decade.

Who does prostate cancer affect?

The majority of men are aged over 60.

What causes prostate cancer?

More is now known about the genes and molecular mechanisms involved in the development of prostate cancer, however further genetic variants remain to be discovered. Men with a brother or father with prostate cancer have a two to five fold increased risk, depending on the age of their relative at the time of diagnosis.

Is the chance of developing prostate cancer influenced by dietary or environmental factors? Is there anything I can do to reduce the risk of developing it?

Obesity, a diet high in animal fat and low in fresh fruit, vegetables and fish and being exposed to cadmium (a heavy metal) or "radiation" have been identified as possible risk factors which may be associated with prostate cancer. However research is still continuing in this area.

What are the symptoms of prostate cancer?

It has few symptoms in its early stages. When symptoms occur they may include difficulties in urinating or pain and/or stiffness, usually in the lower back and hips. However, these symptoms are more commonly caused by other conditions, such as benign (non-cancerous) enlargement of the prostate or arthritis. If you have concerns, you should consult with your doctor.

How is prostate cancer diagnosed?

Diagnosis methods include:

- The PSA Blood Test, which tests the level of 'Prostate Specific Antigen' in the blood;
- Digital rectal examinations to feel the prostate gland and biopsies which take tiny samples of tissue from the prostate.
- The PSA test is not specific for cancer and 'raised' levels can occur due to benign enlargement or inflammation of the prostate gland. Microscopic examination of the biopsy is required to confirm the presence of cancer.

How is prostate cancer treated?

Some prostate cancers grow so slowly that no treatment is needed. Instead, a policy of Active Surveillance is employed to monitor the condition. When more active treatment is required, surgery, radiotherapy, hormone therapy or a combination of these treatments are used. Both radiotherapy and prostatectomy are used in the UK.

Will any treatment affect my sex drive and will I still be able to father children?

Different treatments for prostate cancer can cause impotence, reduced ejaculation, a lowered sex drive, urinary incontinence, bowel problems, hot flushes and sweats and tiredness. Surgery, radiotherapy and hormone therapy all have different side-effects which need to be considered in any decisions about treatment. Treatment for prostate cancer is likely to cause infertility. This should be discussed with your doctor before you start treatment.

I have heard about PSA screening. Is it necessary for all men over a certain age to be screened?

The PSA test (Prostate Specific Antigen) can be used to screen for early prostate cancer. A raised result does not necessarily mean you have cancer and a positive biopsy is needed to confirm cancer which will occur in about one man out of every five. If prostate cancer is diagnosed, it is not necessarily life threatening and curative treatment many not be required – as most men diagnosed with early prostate cancer following a positive PSA test would be expected to have slowly growing cancer which should not cause any problems during their natural lifespan. There is controversy about whether PSA testing should be used in routine screening for prostate cancer. Many medical professionals feel it will be wrong to introduce national screening in this country because the effectiveness of screening is uncertain and the side effects of treatment can be significant. However every man over 50 has a right to a PSA test if they request it and in the USA many men have regular PSA tests from the age of 50.

"Wishing you all a very happy new year for 2010 from Clare, Jenny, Helen and everyone in Urology"

Designed and produced by the Department of Medical Illustration & Graphic Design, New Cross Hospital, Wolverhampton, WV10 OQP Tel: 01902 695378

WCA 1623 11.12.09