

NEWSLETTER

Published by the Norfolk & Waveney Prostate Cancer Support Group
Registered Charity No. 1108384

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FREE

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1st Anniversary issue

From the Support Group Chairman :

We now start our second year of activity, and a word of thanks is due to the hardworking members of your Committee and the Urology Nurses, whose continuing efforts have done so much to get the Group off to a flying start. Thanks are also due to the NNUH authorities for their encouragement, and allowing us the use of their excellent venue facilities free of charge.

We are all here to help you, and we offer a warm welcome to all to our open meetings, and particularly to those newly diagnosed patients, (of whom there have been another 350 since the Group was formed). We hope that the talks, and social gatherings after, have given a measure of reassurance to those concerned about diagnosis and treatments, by being able to talk informally to those of us who have already travelled along this road. We have been encouraged by the attendance figures, the opportunity to raise questions of the medical staff and the comments you have passed back to us.

This year will see an increasing awareness, both nationally and locally, of Prostate problems, and an encouragement to men with urinary symptoms not to "sweep them under the carpet", but to seek medical advice. There is much that can be done.

As an official registered Charity, your Support Group is now one of 46 Prostate Cancer Support Groups working together across the United Kingdom, under the umbrella of the National Prostate Cancer Charity. This organisation has the ear of Government ministers, and leading surgeons, and hosts the National Prostate Cancer conference, to which your Group sent delegates last November. This gives us access to the latest information on research programmes, trial treatments, screening and assessment issues.

Finally, we must not forget those of you living alone, who would welcome a friendly chat, and perhaps cannot attend our meetings. If you know of any member, (or non-member), who might like a visit, please let us know.

The Committee and I look forward to your continuing support in working on your behalf, with my Best Wishes,
David Haines - Chairman.

Project 2001 - "Spring in action"

- invite you to this event in aid of the Norfolk & Waveney Prostate Cancer Support Group at **East Tuddenham Jubilee Hall**

on **Wednesday April 13th** from **11.00 a.m. to 3.30 p.m.**

Tickets £15.00 to include morning coffee and lunch with wine.

Mr Ian Stanton will give a demonstration on hanging baskets, followed by entertaining recitations with Doreen Fish. Stalls and Raffle.

Tickets from:

D Waymark 01953 604879 E Humphrey 01508 492709 P Montgomery 01603 452964

Norfolk & Waveney

**Prostate Cancer
Support Group**

Patron: Martin Bell OBE
www.prostatesupport.org.uk

Registered Charity No. 110838

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Visit our website :

**You will find information about the group, our constitution, committee activities and useful links
If you have access to the internet go to**

www.prostatesupport.org.uk

Charity Status Bid - A Success!

As you will see from the front page (see - title header), our application for charity status has been accepted and we are now officially registered. The charity status came into effect as of 2nd March 2005.

The benefits are tremendous allowing significant tax advantages both in terms of fundraising as well as access to reduced rates for goods and services and access to a variety of grants with a number of local and national institutions.

Using "Gift Aid" - (a special Inland Revenue arrangement) as long as you pay tax in the UK, a gift say of £10 will be worth £12.82. As we will be able to reclaim the basic rate tax on the donation. More details will follow. The person making the donation will need to sign a declaration that they wish to make the donation under Gift Aid. Then we claim back the money.

If you run a business or are self-employed your donation can get tax relief when made under the scheme. Visit the Inland Revenue website if you want more detailed information;

www.inlandrevenue.gov.uk/charities/leaflets.htm □

Making informed choices.....

(This article appeared in March 2005 issue of Saga Magazine. For an annual subscription £17.95, please contact : 0800 056 1057.)

You've just turned 60, and have been newly diagnosed with prostate cancer. Although diagnosis of any form of cancer is always a shock, the good news is that there are now treatments for prostate cancer that can make real difference. The bad news is that patients will

sometimes have to make difficult choices between treatments that could affect the rest of their lives.

Most diseases have one or two effective treatments, while a few might have three or four, but prostate cancer has more than twenty. "You can cut it, you can heat it, freeze it, burn it, fry it - there are all sorts of treatments. And there is no golden rule as to what you should do," says Dr Mark Emberton, Consultant Urologist and senior lecturer at University College London. And Roger Kirby, Professor of Urology at St George's Hospital, warns: "Currently perhaps a third of men when confronted with locally advanced prostate cancer needlessly risk losing their sex lives by making the wrong treatment choice."

By the age of 40, one in four men will have some enlargement of the prostate, although in most cases the growth will be benign. If you have problems with urination or erection, your GP will probably send you for a blood test to measure your prostate specific antigen (PSA) level. In healthy men, this will be below 4 micrograms per litre, but while a higher level can be a clue to possible cancer, the test has limitations as a diagnostic tool. Two out of three men with a raised PSA level do not have prostate cancer. An increase can be the result of benign disease, exercise or sexual intercourse.

However for around 26,000 men a year, the diagnosis is cancer, and the disease now kills more than 10,000 men annually. Prostate malignancies are increasing and no one really knows why, although it is explained in part by the fact that people are living for longer and thus have more time to develop the disease. There is increasing evidence that diet is implicated too, as the huge difference between rates in developed societies and traditional cultures suggest that Asian cultures suffer less from prostate cancer. One

study found that only 1.8% of men in China develop prostate cancer, compared with 53.4% of American men.

One of the reasons why there are so many treatment choices is that no single treatment has been shown to be greatly superior to another, so in many cases, men with similar tumours may be treated differently. "Choosing a treatment at any stage of prostate cancer can be very difficult," says Dr Chris Hiley, Head of Policy and Research at The Prostate Cancer Charity. "It requires a close partnership between the doctor and the man with prostate cancer, to make sure that there is the best fit between the effects on the disease and the side effects on each man's life."

"The working of this partnership is doubly difficult when it is established at a time when the man is anxious, vulnerable and in need of reassurance. As a result of these difficulties, some men may not be offered choices, and this has to change. Men should be helped to make informed choices. It is their body, their health, under discussion."

To encourage that dialogue, urologists have now developed a tool designed to help doctors and patients make the right choice. The so-called Vitality Index is designed to encourage doctor and patient to talk about the available treatments and side effects. It takes into account a man's quality-of-life preferences and priorities, looks at the relative importance of side effects, like incontinence and impotence and the trade-offs between them. The idea is that by working through the index together, a man and his doctor can find the right individual balance.

These are the key choices:

Watchful Waiting :
If the cancer has not spread, one option is to do nothing

but monitor it and see what happens. The most obvious candidates for this approach are older men whose tumours are small and slow-growing. A number of studies have found that, for at least 10 or even 15 years, the life expectancy of older men treated with watchful waiting is not markedly different from that of men treated with surgery or radiation. Many prostate cancers are not aggressive and patients will die from other causes, so this approach, particularly for older men, means they avoid unnecessary treatments.

Hormones:

Hormone-based therapies work by cutting off the supply of male hormones like testosterone that fuel the tumour's growth. They are particularly useful when the cancer has spread beyond the gland and so is beyond the reach of surgery or radiation therapy. The main types are anti-androgens that block the activity of any male hormone and pituitary down-regulators that block the testosterone secretion from the testes, cutting off hormonal stimulation. While they are effective, side effects can include loss of libido and bone thinning.

Surgery:

This is often best suited to men under 70; older men are more likely to be offered radiotherapy because complications with surgery increase with age. Radical prostatectomy is an operation to completely remove the prostate gland and is aimed at men whose cancer has not spread through the covering of the gland. "All major surgery carries a risk of impotence of around 70% and of severe incontinence, 5%" says the Prostate Cancer Charity.

Radiotherapy:

This can be carried out even if the cancer has spread through the covering of the gland, although it must still be quite localised. External beam radiation can help to shrink tumours and relieve pain. The treatment is pain-

less and each session lasts for only a few minutes and is usually given on weekdays for up to six or seven weeks. In conformal radiation, the beams are targeted to avoid damaging healthy tissue. Radiotherapy has none of the risks of surgery and doesn't require you to stay in hospital overnight. Disadvantages include possible damage to the bladder and rectum (around 5%) and a risk of impotence and incontinence in up to 20 - 30% of patients. Diarrhoea and cystitis are common short-term side effects.

Brachytherapy:

Slow-release radiotherapy seeds are implanted in the tissue of the prostate. High-tech scanners guide needles which deliver the tiny seeds in a procedure which takes about 60 minutes. It may sometimes be used in conjunction with radiotherapy and hormone treatment. Side effects can include a burning sensation while urinating which may last for some time. Long-term effectiveness has still to be assessed in large numbers of men.

Less widely used therapies include cryosurgery for freezing and killing localised tumours; ultrasound, which uses sound waves to kill cancer without damaging healthy tissue; lasers for localised treatment that does not damage surrounding tissue; photodynamic therapy, in which the cancer cells are sensitised, then "zapped" with a laser; and chemotherapy combined with hormone therapy for advanced cancer.

The future might see gene therapy and anti-cancer vaccines.

For more information go to: Saga Resource Centre www.saga.co.uk

Associated with the above story

was this personal account....

"Paul Norris has been there, done that....."

In May 2003, aged 65 and one month into my retirement, a six month French caravan tour beckoned. Then my GP diagnosed an irregular heartbeat.

The cardiologist quickly rectified it with electric shock treatment and as a precaution ordered a range of blood tests for me. Later my GP phoned me to discuss a raised prostate specific antigen (PSA) level. "What's that?" I asked.

"Probably nothing serious - it's to do with the prostate" my GP replied. A digital examination followed - it's not as bad as it sounds. Then I was referred to a urologist who did a biopsy via the rectum - my knuckles turned white as I gripped the couch! Ten days later looking me straight in the eyes, he said, "I regret you have a tumour."

I was too stunned to follow the discussion of the pros and cons of radical prostatectomy, radiotherapy and hormone treatments. Fortunately my worried wife Sheila was with me, as my mind was blank with shock.

A 20-day radiotherapy course plus hormone injections followed - there were no side effects except tiredness. The hormone treatment is straightforward chemical castration - I am now impotent but it's an advantageous trade-off against a possibly fatal alternative.

My PSA has dropped from 13.2 to absolute zero - great news. Although one in three men with PSA between 4 and 10 will have cancer; a raised level only indicates a possible unhealthy prostate, not definite cancer.

I am very fortunate that the cardiologist diagnosed the

raised PSA - the tumour had probably been growing for about five years but I had never even heard of the PSA test. Men's lack of prostate cancer awareness is appalling - we are wimps about visiting doctors. If you have difficulty with or increased frequency of urinating, or brewer's droop without the alcohol - see your GP.

This year I plan to backpack from northern France to Montpellier on the Med. Despite my treatment I feel fit and ready to cope with the 750 miles. By writing articles about this walk, I hope to increase public awareness of the disease. Sheila and I enjoyed our French caravan tour last year and, thanks to that initial irregular heartbeat my future looks rosy. "

This article was also courtesy of Saga Magazine.

Editor's comment :

Paul Norris's story made me think of my own recollection of that first meeting after diagnosis and how I too was grateful for the presence of my wife. It reminded me how important the support of our partners and family is. They can often be neglected, as all the attention is focused on the "patient". But they too share the anxieties and often without the direct support offered to patients. The support Group is there for them too!

At our last Open Meeting we tried a new experiment with setting out the tables after the lecture. They were arranged by treatment method and included one for partners and family.....

.....Is this a good idea ?

please let us know - we are anxious to know what you think. - 'Cos if you don't like it we can change it !

Some useful Contacts and sources of information.

The Big C Appeal

Norfolk and Waveney's independent local cancer charity funding research, treatment equipment, care and support
10a Castle Meadow, Norwich NR1 3DE
Telephone 01603 619900
www.thebigcappeal.co.uk

The Evening News

www.en24.co.uk

The Prostate Cancer Charity

National organisation with information and helpline.
3 Angel Walk
London W6 9HX
Tel: 020 8222 7622
Fax: 0208222 7639
e-mail: info@prostate-cancer.org.uk
website: www.prostate-cancer.org.uk

Prostate Help Association

Support network, newsletter and a book on prostate cancer.
Philip Dunn,
PHA,
Langworth,
Lincoln LN3 5DF

CancerBACUP

Cancer nurses provide information, support and advice telephone or letter. Newsletter, booklets, factsheets website and CD-ROM.
3 Bath Place, Rivington Street
London EC2A 3JR
Freephone 0800 800 1234
Fax 020 7696 9002

If you've finished with the newsletter and do not need it anymore, why don't you pass it on to someone who may not know of our activities.

Editor.....stefan ganther

**An evening with Martin Bell OBE
at The Noverre Suite
Assembly Rooms, Norwich**

**"Television, war & politics"
Saturday 4th June
7:30pm
Tickets £10 each**

Available from committee members,
Urology Nurses NNUH or ring
01603 713463

**Do you need
help with
transport
to and from
our meetings ?**

If you are unable to get to our meetings because of transport difficulties then contact : 01603 289845. The nurses will pass on your details to the nearest member so that you can share the journey. We will try to pick you up and return you home following the meeting.

**How to
Contact us :**

write to :

**Norfolk and Waveney
Prostate Cancer
Support Group.
Urology Dept.
Norfolk and Norwich
University Hospital.
Colney Lane
Norwich
Norfolk
NR4 7FP**

telephone :
Urology nurses on:
01603 289845

e-mail :
stef.g@care4free.net

Visit our website :
www.prostatesupport.org.uk

for letters to
the editor write to :

**Newsletter
Home Farm Cottage
The Drive
Hoveton
Norfolk
NR12 8JE**

**We welcome news
items or notices of
any local fundraising
or other activities in
connection with our
charity.**

**It is
- what you make it !**

The Norfolk & Waveney
Prostate Cancer Support
Group is a registered
Charity, No. 1108384.

This edition has been
sponsored by
Waveney District Council.

Dates for your Diary

- 4th April 7 p.m.** Open meeting at NNUH
Talk by Suzie Capon, Contenance Adviser, on "Contenance Issues", followed by **AGM** and Social Hour.
- 13th April** " Spring into Action" Project 2001 invite you to this event in aid of the Norfolk & Waveney Prostate Cancer Support Group at East Tuddenham Jubilee Hall on Wednesday April 13th from 11.00 a.m. to 3.30 p.m.
- 9th May 7 p.m.** Committee meeting NNUH
- 4th June 7.30 p.m.** Fundraising Event – "**An Evening with Martin Bell**"
Assembly Rooms, Norwich
Tickets £10 each from Committee members and Urology Nurses, NNUH
- 6th June 7 p.m.** Open meeting at (**NOTE :**) **JAMES PAGET HOSPITAL**
Talk by Mr G Suresh, Consultant Urologist, on "Surgical Treatment / Intervention"
- 4th July 7 p.m.** Committee meeting NNUH
- 1st Aug 7 p.m.** Open meeting NNUH
Dr Janet Campbell will give a **GP's perspective** on Prostate Cancer, followed by Social Hour.
- 5th Sept 7 p.m.** Committee meeting NNUH
- 3rd Oct 7 p.m.** Open meeting NNUH
Dr Jo Edwards, Clinical Psychologist will speak on **Urinary and Reproductive dysfunctions**, followed by Social Hour.
- 7th Nov 7 p.m.** Committee meeting NNUH
- 5th Dec 7 p.m.** Open meeting at NNUH
Dr Marek Ostrowski, Consultant Oncologist will speak on the latest developments in **Brachytherapy**, followed by Social Hour.

We also hope to arrange one or two social events during the summer. If you have any particular ideas or suggestions, please let the Editor know.