

NEWSLETTER

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

Norfolk & Waveney

Prostate Cancer
Support Group

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

Registered Charity No. 1108384

Issue No.4

FREE

6th June 2005

A report on the 1st AGM held on 4th April 2005

73 members (approx. 30% of registered members) including the committee, attended last month's AGM. Perhaps contrary to expectations, the meeting proved most enjoyable and a special thanks to Suzie Capon who gave a talk on "continence issues" which was most entertaining despite the subject matter. There we were, all doing pelvic thrust exercises together in the lecture theatre. It would have made a good picture !!

The business of the AGM was carried out and the committee, who all volunteered to continue, were voted in accordingly. The Chairman hoped that some new members would come forward to join the committee, in the coming months and share in the running of the Support Group. He also urged members to consider organising local events, fundraising or simple social gatherings. They all help to raise awareness of the disease.

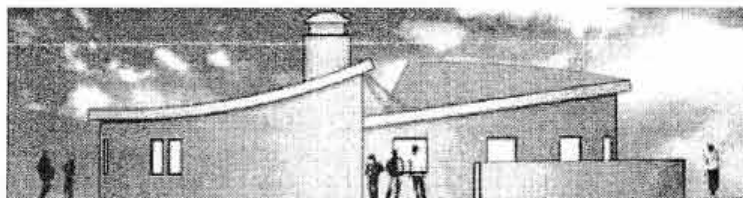
Editor's comment: I would like to take this opportunity, on behalf of the committee, to extend our warmest thanks to the specialist nurses (Sally Jermy, Claire Fullalove and Wendy Baxter) without whose support and energy we would not exist. A special message to Wendy - "we send our best wishes and good luck with the impending arrival of a little Baxter."

These links ensure our ability to support each other and inform, on a wide variety of initiatives. Your group is now represented on the Government sponsored Norwich Patient and Public Involvement Forum. This is a body whose role is to review local health services with input from patients and the public and to influence the local decision-making process in determining current and future services. Any comments or complaints from members on these matters can be taken up with the Forum - contact the Chairman.

Finally, I would like to repeat the Chairman's request for NEW BLOOD to join the committee. The present committee has worked hard over the year and should be congratulated on its achievements. However it is true to say that some of our committee may appreciate spending a little more time on themselves - I think they deserve that support - from the rest of us !

Anyone who would like a copy of the minutes should contact the committee secretary,

The BIG C centre - breaks ground.



Work has begun at the NN University Hospital site in a ceremony where the cutting of the First Turf was carried out by Richard Jewson. Janice Hulett, fundraising co-ordinator, says, "It can be difficult knowing where to turn once you've received your diagnosis and it's hard to take it all in. A visit to the centre will offer time and support for each individual".

Despite the fact that work on site has started, the fundraising campaign for this centre has still a long way to go. Make sure you spread the word about this project which your group is fully committed to supporting. As you know your committee is in discussions with the Big C and as soon as we have more information on how we will be involved, we will let you know. It is likely we will have "a presence" at the centre as it is envisaged it will rely on a lot of volunteer support. If you think you would be interested please contact our chairman or the secretary, in the first instance.

If you are interested in finding out more about how you can financially support this project visit the Big C website (details inside). See the Dates for your Diary section also for details of one event we think might interest you! Remember meeting other people at such events is another way to help promote our own group and achieve one of our aims which is of course to increase awareness of the disease. □

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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

Gift Aid - How does it work?

- Every £1 given, can be turned into £1.28 at no cost to you.
- First of all you need to be a UK taxpayer.
- To qualify for Gift Aid, what you pay in income tax or capital gains tax must at least equal the amount the charity will claim in the tax year (currently that means 22% of the gross equivalent of every pound you donate).
- However you make a donation, you need to make a Gift Aid Declaration. This can be backdated to 6th April 2000 and set in place until otherwise notified.
- A Gift Aid Declaration requires your dated signature and a request that your donation(s) are treated as Gift Aid.
- Cheques and/or postal orders should be accompanied by such a form.
- In order for us to claim gift aid on the cash donations you have made at our meetings so far we would appreciate it if you would kindly sign and return the cut-out



Gift Aid Declaration

If you are a UK taxpayer please sign the declaration below. (The value of your gifts will increase by 28% as we can reclaim the tax you have already paid on them). I CONFIRM I AM A UK TAXPAYER.

Please treat all my donations I have made since 6th April 2005 and until further notice as Gift Aid.

My annual income tax and/or capital tax payments are more than the amount the Norfolk and Waveney Prostate Support Group will claim.

signature.....date.....

Please send your reply to:
Norfolk and Waveney Prostate Cancer Support Group
Urology Dept.
Norfolk and Norwich University Hospital
Colney Lane
Norwich
NR4 7FP

Registered Charity No 1108384

Thank you for your co-operation in this matter. It makes a big difference.

You can also let us know if you are interested in the "Evening on the Broads - River Trip" by ticking the box and identifying numbers.

Yes, I would be interested in the river trip.



I would be interested in bookingplaces

"Prostate Cancer counselling should include partners...says a recent report

"A recent study of 103 couples in which the man was newly diagnosed with prostate cancer found that patients' partners generally had more symptoms of depression, anxiety and other negative emotions than the men themselves did.

Emotional distress over a prostate cancer diagnosis and any resulting sexual dysfunction can affect how a man manages his disease -- whether that distress is his or his partner's -- according to the study authors, led by Dr. Cynthia T. Soloway of the University of Miami School of Medicine.

The new findings, they say, suggest that wives and other partners should be included in prostate cancer treatment decisions, and in counselling throughout patients' care.

"The results...underscore how important it is to hear the voice of the couple," Soloway and her colleagues report in the British Journal of Urology International.

Their study included 103 men between the ages of 43 and 80, along with their female partners, mostly wives. Many studies, according to Soloway's team, have looked at quality of life after a prostate cancer diagnosis, but comparatively little is known about how the disease affects the relationship between men and their partners.

On standard questionnaires, women generally reported more symptoms of depression, anxiety, anger and

confusion than men did. They also rated their partners' sexual performance and ability to maintain erections as poorer than the men did themselves.

Erectile dysfunction is a common side effect of prostate cancer treatment, and one of the implications of the current findings, according to Soloway's team, is that women should be included in discussions about treatment and its possible side effects.

In addition, they say, the high rate of emotional distress among partners points to a need for counseling. At diagnosis, the researchers note, nearly a third of the couples in the study could have been referred for psychological care.

But, they add, whether patients and partners are in fact routinely evaluated for depression and referred for treatment is unclear.

"The present study," Soloway and her colleagues conclude, "provides evidence that the prostate cancer 'couple' at diagnosis has complex and disparate needs, and shows a need for psychosexual interventions that augment current treatments for sexual and psychological problems arising from a prostate cancer diagnosis."

SOURCE: British Journal of Urology International, April 2005.

The above article is extracted from the Prostate Cancer Charity website and is taken from a recent Reuters News item.

"Let's be havin' you....."

We really would like to hear from you with stories or news items for the newsletter. Help us make this work. You can contact us in many

Letters to the Editor

dear editor

I thought readers may be interested to know of two publications which I found most useful in understanding prostate cancer and helped me to decide on what treatment I preferred to undertake, luckily I had a choice. The 'Tool Kit' which is free from the Prostate Cancer Charity Tel No 020 8222 7622 is essentially a collection of leaflets on various treatments for PC and include a series of questions to ask GP's and PC Specialists.

The 'Tool Kit' also includes leaflets on for example, Hormone Treatment, Pain Management, Diet for men with Prostate Cancer, etc.

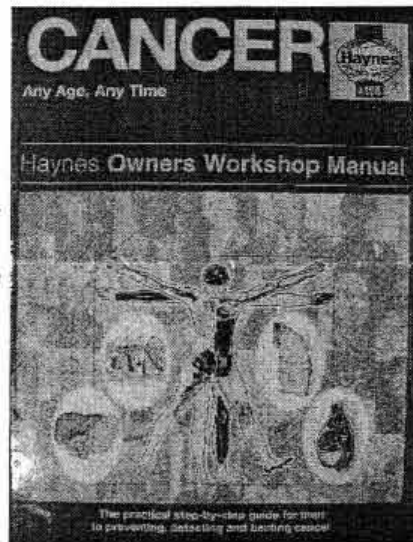
The other book I would recommend which was suggested to me by the excellent NNUH specialist nurses, was Haynes Workshop Manual - Cancer. This is in the same format as a typical Haynes car manual which most men will be familiar with (there is no need for this manual to have greasy marks all over it!).

Although this manual covers common cancers, the chapter entitled 'Pipes and Hoses' includes prostate cancer and provides the illustrator with adequate scope to have a little fun with our private parts!

The text is readily understandable and although obviously I was particularly interested in the PC section I found the other chapters such as 'Air intake System' (respiratory) and the Hydraulic System (Blood) interesting. And when you read the Engine management System (Brain) you are pleased you only have Prostate Cancer!

I obtained my copy of this book on-line at www.amazon.co.uk for £9 plus P&P.

I would like to thank you for providing this useful newsletter
dave cole



Thanks for the kind words, Dave. Thank you also for sending in this piece for the Newsletter. It is pleasing to know it is of use and interest. Hopefully your contribution will encourage more members to pass on their experience - or anything they think may interest fellow members. E-mail or a letter is not a lot of effort when you imagine your information may help someone make a better choice for their own future and that of their families. My own experience was that I too got hold of a good booklet by Philip Dunn (details in our colour A4 -folded pamphlet) which had an excellent 'Tool Kit' identifying the questions which will give you the most from the initial and most important meeting with the consultant, so that you can make that all important choice with as much background as possible. Those first moments are the most difficult because of the uncertainty and lack of knowledge. One thing for me was that I was not at the first meeting, because quite honestly if my wife had not been there to make notes I do not think I would have remembered anything simply because there is a lot going on 'in there' at that time!!

Editor.

Next Meeting

**Tuesday 2nd August, East Atrium NNUH at
7pm - 8:30pm
"A GP's Perspective".**

Dr Ian Hotchin is a GP, based in King's Lynn, with a special interest in prostate cancer. This interest extends to his doing regular weekly clinics at the NNUH, where he does biopsies etc.

As usual the talk will be followed by an opportunity to meet and talk to fellow members in a relaxed atmosphere. We will continue to arrange the tables according to treatments.

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 by telephone or letter. Newsletter, booklets, factsheets website and CD-ROM.

3 Bath Place, Rivington Street, London EC2A 3JR
Freephone 0808 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

A Big Thank You to; -

- * Roy Medcalf of the Masonic Fly-fishing Association for their donation of £100.
- * A. Barnes of the Hoveton Country Dancers Group for their donation of £40.
- * Pam Coldham of Project 2001 Fundraisers, who are working on our behalf this year and £750 was raised at the recent "Spring into Action" event at the East Tuddenham Village Hall where the chairman gave a presentation on our group and activities. Thank you to all those who made this such a success!
- * All of you for participating in our efforts!

Keep it up ! (In more ways than one!) and don't be shy !
Remember the group is only 'the sum of its parts' and **that means you!** - Not just the committee. Spread the word and help raise awareness of prostate cancer and that
there is life after diagnosis !

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 713463**
Stan 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

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.

Dates for your Diary

- 6th June 7 p.m.** Open meeting at (NOTE :) **JAMES PAGET HOSPITAL**
Talk by Mr G Suresh, Consultant Urologist, on "Surgical Treatment / Intervention"
- 26th June Sun.** **10am - 4pm.** "Walk of Thoughts" A Big C event where you can enjoy the grounds of Somerleyton Estate and raise funds at the same time. See above for more details.
- 4th July 7 p.m.** Committee meeting NNUH
- N.B. Tuesday 2nd Aug 7 p.m.** Open meeting NNUH
Dr Ian Hotchin 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.
- 3rd Nov all day** **2nd National Prostate Cancer Conference** London.
More information in future issues.
- 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 the Social Hour.

Are you interested ?

We are considering holding a social / fundraising event with "an evening - on the Broads".

A river trip with refreshments and your good company. (Late summer)

Ticket prices will depend on interest from the group.

Please be kind enough to ring us with an expression of interest.

We would need to know ASAP. See inside for reply form.