

Norfolk & Waveney
Prostate Cancer Support Group
NEWSLETTER

Issue No 14

February 2007

Prostate Cancer Awareness Week

Prostate Cancer Awareness Week is an annual health awareness campaign organised by The Prostate Cancer Charity. This year it will run from 19th to 25th March. It aims to raise the profile of prostate cancer among the general public and in the media.

Hundreds of individuals and groups across the UK join forces to help raise awareness of prostate cancer and raise vital funds to improve research, information and support services for men and their families who are affected by this disease.

Please do your best to "spread the word" to your friends and their families.

Cryo-Ablation Trial NNUH

Many of you will be aware that the trial is now under way. The first two patients were successfully treated on 11th December, and the next two on 18th January. Mr Edwin Ho, the surgeon conducting the trial, has told us that all went well, with the patients being discharged after overnight observation, and to date no problems have come to light, although they will be monitored for some time to come. Assessment continues with other patients for eligibility to receive this treatment. Offering financial support for this project was our leading objective during 2006, and thanks are due to all those who have given so generously to this end. We wish Mr Edwin Ho and Mr Rob Mills, NNUH Consultant Urology Surgeons and their team every success, and hope that we will eventually see this procedure as a permanent option for Prostate Cancer patients in Norfolk.

Appeal for Volunteers

We are facing some difficulties in ensuring the future continuation and development of the Group in its present form, following the loss of several founding Committee Members during the past year due to ill-health and other responsibilities. The original plan was to elect members of the Committee to serve for a period of one year, subject to re-election if they so agreed. In the event over half of your Committee have now served for three years, and during this time have established the Group as a registered Charity, and given it

credibility and visibility across the county, making a wide range of information available through our open meetings and publications, and offering support to many people through our help line contacts. If you would like this to continue and you are in reasonable health with a few hours to spare each month, please consider joining the Committee. We need to elect a new Chairman, Vice-Chairman, and Secretary to serve in the coming year, and those with experience in such areas within a small organisation will be most welcome.

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Radiotherapy Department Open Evenings

The Radiotherapy Department holds Open Evenings on the first Wednesday of every month at the Colney Centre, NNUH. The next Open Meetings will be on **Wednesday 7th February** and **Wednesday 7th March** from 6.00 to 7.30pm. Partners, relatives, carers and friends are encouraged to come along.

The Open Evenings are billed as an opportunity to:

- Meet the Team
- See the Treatment Machines
- Voice your Concerns
- Ask Questions.

For further information or to book a place, simply contact the team on 01603 288779.

Your Editor takes the Radiotherapy Department Tour



CT SCANNER, COLNEY CENTRE NNUH

As I was about to embark on a four week course of radiotherapy, I was much reassured to see for myself how the department operates. Tours are in two groups, men (usually prostate cancer) and women (usually breast cancer). A senior radiographer was our guide. We were shown the CT Scanner and Simulator. These take very accurate pictures and are used for planning the treatment of each patient. The Simulator looks like the treatment machine but its function is to take X-Rays.

Then we were shown the Real Thing – the powerful and incredibly accurate Linear Accelerator which administers the radiotherapy. Thin green beams are used to line up the patient in exactly the same position for each treatment. The patient's contribution to this is to have three tiny permanent tattoos, one above the pelvis and two on either side. Our heroic guide had even

had his hand tattooed to show us how small the marks are. The beams are aimed precisely at the tattoos, with the patient being gently pulled this way and that until the alignment is perfect. The maximum tolerance is 3mm – we are dealing with perfectionists here!

Our radiographer guide encouraged what proved to be many questions, and was careful to cover all the potential side effects – so that we would be left with no surprises during treatment.

The result? When I came to have the three preliminary planning sessions and then the treatment itself, I knew exactly what to expect and was not intimidated by the formidable machinery because I knew exactly what was happening and why.

As for the radiographers, there is only an "A Team" – they really know what they are doing!



LINEAR ACCELERATOR, COLNEY CENTRE NNUH

Martin Bell at the Big C / NWPCSG Christmas Lunch

Many Members of the Committee and our Group enjoyed a Christmas fundraising lunch at the Maids Head Hotel on 1st December, held in conjunction with Big C. Our Patron, Martin Bell, attended and gave us an update on his activities in Afghanistan for UNICEF, for whom he is the UK Ambassador. Two days before he had been in Kabul, travelling back with Azerbaijan Airways via Moscow, a trip he did not recommend. Shortly after our event Martin was due in Basra. As well as his Charity work, he is kept busy as a freelance reporter from the world's troublespots. Watch out for his forthcoming documentaries on Channel 4, and his new book. The event raised around £1,000 for Prostate Cancer projects supported by us and Big C.

Arnold Palmer Drives into the 10-Year Club

Legendary golfer Arnold Palmer has just achieved another milestone in his amazing life – it is exactly 10 years since he had a radical prostatectomy. He was 67 when he had the operation and now, at 77, he's still going strong!

Ever with a positive attitude, his comments on his prostate cancer are encouraging for all of us.

"Enjoying good health is especially important on the golf course, so I have been in constant touch with my doctors over the years. They had given me the results of my annual PSA tests so I was aware that my prostate was acting up a little bit. I guess I was aware of what might happen, but I had no idea that anything was wrong. I didn't have any feelings and, as far as my personal health habits were concerned, nothing had really changed."



"I guess most of us would rather not discuss cancer because we are all afraid we might be told we have it. It's hard for people to even say the word, and that's the first obstacle you have to overcome when you are diagnosed with the disease. I think once you understand a little more about it... I don't mean it gets any easier...but I think you give it more in-depth thought about how you're going to deal with it."

Palmer says he has a lot of confidence in his doctors, at the time of his diagnosis and now.

"I believed strongly in what they were telling me. I decided I was going to the Mayo Clinic — where the diagnosis was confirmed — and then I proceeded to get on with what was necessary. They told me the bottom line on what I had, where it was, and how to treat it...and I accepted that. While I certainly had all the options to do whatever I wished, as far as the treatment was concerned, I chose the aggressive option. I chose surgery, and I'm happy with that decision. I was fortunate to experience no side effects, other than the recovery period which was, to me, rather lengthy. I looked at it like this: if you're recovering from cancer then you're in a pretty good mode, and should accept it. Yes, indeed, I'd make the same decision again."

About eight weeks after surgery, Arnie was back on the golf course.

"I discovered that I was somewhat weak. I didn't have the strength that I felt I used to have. This is certainly a consequence of surgery and you have to be ready for that. I'm still not totally at full strength, but I'm also getting older, so that may have something to do with it."

Arnie is concerned that men need to make the commitment to maintaining good prostate health, and he offers some sound advice on the subject:

"Just get your regular check-ups and PSAs and, if you're diagnosed, do everything you can to eradicate the disease. I think we are fortunate to have the best doctors in the world in this country. If you're not satisfied with the diagnosis and prognosis, then get another couple of opinions. But, in the final analysis, you need to do what it takes to get rid of the cancer and get on with your life."

Palmer says that a lot of men have come to him and said that they are getting their PSAs because they have heard him recommend it.

"I know that there are also a lot of men who are NOT getting a regular PSA. I don't know how you can convince them that this simple test might just save their life. I guess we just have to keep saying it over and over, stressing that this is something that is really very necessary. This is also an area where I think it the federal government has a major role to play. The government is, after all, the people. They have a responsibility — in addition to funding research — to help translate this message to the general public."

Palmer is very stoic about being a cancer survivor. "I think there is always the potential that, once you have been diagnosed with cancer — depending on your age and attitude on life — that this can affect your personality. I would hope that we can overcome whatever ill effects that might have on us, and get on with enjoying life."

A Big Thank You

We have received further donations since our last Newsletter, and thank all those concerned for their support:

	£
Project 2001 Ladies Fundraiser – Christmas event	1,472.50
Ray and Vera Allen (Proceeds of Car Boot Sale, Hingham)	517.45
Mr Ronnie Capps	20.00
Mr S Forrest	20.00
Mr K Perfitt	20.00
Mr T M Semmence	15.00
Mrs S A Bues	12.50
Mr I Newell	10.00
Norwich Valuation Office	9.09
Mr & Mrs V Allum	3.00
Open Meeting 4th December – Raffle	100.00
Open Meeting 4th December – Donations	23.51

Dates for your Diary

Wednesday, 7 February
6.00 - 7.30pm

**Radiotherapy Department
Open Evening
Colney Centre, NNUH**

Monday, 5 March – 7-9pm
**Support Group Committee
Meeting, NNUH.**



Wednesday, 7 March
6.00 - 7.30pm

**Radiotherapy Department
Open Evening
Colney Centre, NNUH**

Monday, 16 April – 7pm

**Open Meeting & AGM,
East Atrium, NNUH**

Jill Chapman, Big C Family Cancer Centre, on facilities now available for Prostate Cancer patients and their families.



Citizen's Advice Bureau

CAB Adviser, Tina Bullen, will be available at the Big C Family Cancer Information & Support Centre every Tuesday to help cancer patients, their families and carers with finance, benefits, housing, welfare issues, etc.

Clients can be seen either in the Centre or on the wards.

To make an appointment please call the Centre on
Tel: 01603 286112 or 286113.
Drop-in appointments may be available on the day.

It is interesting to note that many of our donors, particularly Project 2001 and various clubs, have given us contributions unconditionally, and trusted us to use them in the best interest of Prostate Cancer patients.

We are sad to report the recent deaths of two of our members, Terry Day and Eric Sharpe. Eric's widow, Bobby, said they both appreciated the help and advice we gave, and also the kindness Eric had from the nurses on Knapton Ward, NNUH. She said it was his wish that funeral donations would be shared between Knapton Ward and N&WPCSG.

How to Contact Us

- **Write to:**
Norfolk & Waveney Prostate Cancer Support Group,
c/o Urology Department,
Norfolk and Norwich University Hospital,
Colney Lane, Norwich, NR4 7FP
- **Telephone the Specialist Nurses:**
Sallie, Claire or Wendy,
Specialist Uro-oncology Nurses,
Norfolk and Norwich University Hospital
01603 289845

Angie or Wendy,
Specialist Uro-oncology Nurses,
James Paget Hospital
01493 453510
- **Committee / Help:**
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