

# Norfolk & Waveney Prostate Cancer Support Group NEWSLETTER

Issue No 20

February 2008

## Prostate Cancer Care: the Patient Perspective – A Global Study

Hill & Knowlton, the international public relations company, instigated and financed this study to examine the experiences of patients with prostate cancer. Patients were asked about their experiences within their country's healthcare system, their diagnosis and treatment, and their quality of life. Here are some extracts:-

### Key findings

A cursory glance at the survey findings indicates that the patients in this study are generally very satisfied with their treatment and care. Over 87% report that their current quality of life is "good" or "better than good". A similar percentage – 88% – rate their relationship with their doctor as "good" or "excellent". Over 75% deem as "satisfactory" or even "excellent" the information on treatment benefits and risks supplied to them by both doctors and patient groups. All of which suggests that not much is amiss with the state of prostate cancer care. Not so.

### Major concerns with screening and diagnosis

The chances of being cured of prostate cancer depend on timely access to screening and diagnostic procedures. Yet there were many case stories of healthcare systems failing to prioritise the all-important PSA screening test, and of delays in the performance of biopsies. One patient is refused a PSA by his GP. Another patient's GP is not forthcoming (until too late) about the need for screening. New Zealand's Ministry of Health appears to be against screening. A Canadian patient gets his biopsy too late for a cure to be feasible. And so on ...

### WHAT PATIENTS IN THE STUDY RECOMMEND

- *Government policies that aim to reduce the mortality rate from the disease.*
- *Screening procedures for all men aged over 50.*
- *International recognition for every legitimate treatment.*
- *Healthcare systems (whether insurer or state) should be willing to pay for accepted treatments.*
- *Increased R&D investment in prostate cancer research.*
- *Care to be managed by a team of health professionals.*
- *Guarantees that the team members (including pathologists who check prostate biopsy samples) are sufficiently skilled.*
- *Honesty from doctors about the risks and benefits of treatment.*
- *Patients to be told of treatment choices.*
- *Patients to be involved in medical decisions that affect them.*

Part of the reason the patients can point to a high quality of life is that many have caught their cancer early on, and are cured. Some 42% insist they have been successfully treated, with no remaining signs of the disease. A further 20% say that they have early-stage prostate cancer currently being obliterated. But the clinical outlook of the remaining 48% is far less satisfactory. To continue to survive, these latter patients must constantly monitor and manage their condition.

Much more could be done to enhance the veracity of the tests, which can underreport the severity of a cancer (and thereby deny any such patient the chance to be rid of the disease).

### Clinical incompetence

Participants felt that all of the professionals dealing with prostate cancer patients (including the pathologists responsible for scrutinising biopsy samples) should be expert at their work. The survival prospects and quality of

life after treatment rely on the skills and knowledge of these professionals. If this study is anything to go by, clinical incompetence among prostate cancer care professionals is all too common. Varying standards of ability are reported, with several patients remarking that their doctors' lack of proficiency almost cost them their lives. Then there is a reluctance to consent to multi-disciplinary team-working among surgeons, radiologists and oncologists.

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Teamwork helps patients access the whole repertoire of the knowledge needed to manage the complexities of prostate cancer treatment. But over 80% of the 312 patients in this study confirm that their care is managed only by a urologist (sometimes even without reference to other specialists and carers).

### **Serious shortcomings with treatment AND the need for honesty in patient information**

The wide spectrum of prostate cancer treatments are handicapped by side-effects (which, in some patients, can be severe and long-lasting). The most common side-effects are erectile dysfunction, incontinence and – with hormone treatments – hot flushes and testosterone flares that can promote cancer growth. Although side-effects can, in principle, be offset by other treatments, the approach does not work for everyone. Selecting appropriate treatment depends on the patients age, health, stage of the disease and – most importantly – personal preferences. Unsurprisingly, patients in this study deplore the lack of honesty among those health professionals who 'dumb down' the potential of side-effects, and who fail to pass on to patients information about treatment choices. Quite separately, the study's patients call for more money to be invested in prostate cancer research; ideally, bring spending on a par with investment in breast cancer research.

**Do you want a copy of the full 33 page study?** Just contact Clive Nead (preferably by email) at:- PatientView, Woodhouse Place, Upper Woodhouse, Knighton, Powys, LD7 1NG, Wales  
Email: [info@patient-view.com](mailto:info@patient-view.com) Web: [www.patient-view.com](http://www.patient-view.com) Tel: 015417-520 965

## **Trek to the summit of Snowdon in aid of prostate cancer**



In the UK a man dies of prostate cancer every hour. The Prostate Cancer Research Centre in London is working hard to find a cure. On 17 May 2008 five hundred people will be trekking to the top of the highest mountain in Wales to raise vital funds for the Centre's pioneering research. Sign up now to make sure you are one of them and enjoy a spectacular day out.



For more information about the event and to download a registration form go to [www.snowdon500.co.uk](http://www.snowdon500.co.uk) or call the event organiser Matt Rannamets on **07769 622674**.

## A Most Important Item

We are into the early part of a new year and at last the afternoons are starting to lengthen. Even though the rain continues to fall on most days and we long for that warm sunshine on our backs. The Sunday papers are full of advertisements for holidays, so now is the time to get down to deciding where to spend the next holiday. Whether it be a short break to a European Capital, two weeks at a popular resort, maybe a cruise, or the holiday of a lifetime to celebrate a special occasion.

Whichever one you choose, you still have a further decision, if not the very most important decision to make, Holiday Travel Insurance. If like all of our male members you have suffered from cancer of the prostate gland. When it comes to arranging Holiday Travel Insurance cover and you mention the "C" word. Either your Travel Agent, or if you arrange your own Travel Insurance, you, will be referred to Medical Screening. This can be quite an unpleasant experience, with the adviser seeming not to know very much about your medical condition and if you query anything said to you, they simply return to their script and you land up going round in circles. You invariably find that you finish up with quite considerable loading on the original basic insurance quote.

This need not be the case. Freedom Insurance arranges Travel Insurance for people living with pre-existing medical conditions. Freedom offers a one-stop-shop where advice, a medical screening procedure, a quotation and policy fulfilment can be conducted in a single phone call. Their travel insurance advisers are knowledgeable and compassionate. You will find them eager to provide an insurance solution to fit your particular circumstances. Staff are also trained to receive Typetalk calls.

### Why have pre-existing conditions covered?

Medical costs abroad can be very expensive. Without insuring your pre-existing condition anything arising directly or indirectly from a pre-existing condition will not be covered and you could be seriously out of pocket.

By covering your pre-existing medical condition(s) should you become unwell before departure date and need to cancel your holiday, you will be able to recover your financial losses within the policy terms and conditions.

In the event of your pre-existing condition resulting in the need for repatriation, providing you have adequate travel insurance you will be brought home and protected from financial loss.

**Travel Insurance  
for people living with  
pre-existing medical  
conditions**

  
freedom



All the above will apply to any travelling companions also insured on the same travel insurance.

The writer of this article has used the services provided by Freedom Insurance and has found their travel insurance advisers to be very attentive and sympathetic. In his case the travel insurance premium was considerably less than that quoted by another travel insurance company.

There is a limited number of the latest leaflet from Freedom Insurance for Travel Insurance for people living with pre-existing medical conditions.

Or contact them direct:-

Freedom Insurance Services Ltd, Richmond House  
16-20 Regent Street, Cambridge, CB2 1DB

Tel: 01223 454 290

Web: [www.freedominsure.co.uk](http://www.freedominsure.co.uk)

Email: [information@freedominsure.co.uk](mailto:information@freedominsure.co.uk)

Fax: 01223 720 277

Have an enjoyable holiday and whatever you do,  
**PLEASE MAKE SURE THAT YOU HAVE  
ADEQUATE TRAVEL INSURANCE IN PLACE  
ONCE YOU HAVE BOOKED YOUR HOLIDAY.**

*With thanks to David Wiseman, our Membership Secretary, for this article.*



## A Big Thank You

We continue to receive donations, and thank all those concerned for their support. Acknowledgements are extended to:

	£
In Memory of Michael Hogg. ....	355.00
In Memory of Walter Erith. ....	302.70
The Kitchenary Taverhan Craft Centre. ....	175.00
SWANN Walking Group. ....	84.00
Mr & Mrs M King . ....	50.00
Mr & Mrs L Steward. ....	50.00
Mrs J Jones . ....	30.00
Mr J Cory. ....	25.00
Mr J Newman. ....	25.00
Mr B Provan. ....	20.00
Mr & Mrs B Williams. ....	20.00
Mr T Brett. ....	10.00
Mr A Brickley. ....	10.00
Mr L Earl . ....	5.00
Mrs P Jones. ....	5.00
December Meeting Raffle. ....	116.00
December Meeting Donations. ....	32.30

## Dates for your Diary

Wednesday 6 February &  
5 March 6.30-7.30pm

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

Sunday 24 February  
12 noon - 9pm

**Country Music Charity  
Afternoon, Mulbarton**

Monday 3 March 7-9pm

**Support Group Committee  
Meeting, NNUH**

Monday April 7-9pm

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

# COUNTRY MUSIC CHARITY AFTERNOON

Featuring John C King, Texas Gun & Marc James

Sunday, 24th February

Mulbarton Social Club, The Common, Mulbarton, NR14 8AE.

From 12 noon – Dancing: 12.30 -9.00pm

**Prize Draw, Tombola, Buffet & Bar. Fish & Chips available** (not included in ticket price)

Tickets £9 on the day / £8 in advance from Peter 01603 429547, John 01362 691744, Jane 01508 578327

All proceeds to N & W Prostate Cancer Support Group

## How to Contact Us

### Write to:

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c/o Urology Department,  
Norfolk and Norwich University Hospital,  
Colney Lane, Norwich, NR4 7FP

### Telephone the Specialist Nurses:

**Claire, Sallie 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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01603 881213  
or 01328 862927

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### Visit our website:

[www.prostatesupport.org.uk](http://www.prostatesupport.org.uk)