

prostate matters

Newsletter of the Prostate Cancer Support Federation  Issue 7 February 2010

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Worried or concerned about prostate cancer?

National Help Line

0845 601 0766

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You can download this newsletter direct from our website. Go to:
www.prostatecancerfederation.org.uk/ProstateMatters_latest.pdf

The Federation e mail address is:
info@prostatecancerfederation.org.uk

It is intended to publish this newsletter 4 times a year

*New Year, new layout
and a sponsor for our
new all colour newsletter!*

The Prostate Cancer Support Federation
Annual Conference & AGM

**Living well with
Prostate Cancer**

**Saturday 24th April 2010
11.00 to 4.45pm**

at the

**Penny Brohn Cancer Centre
Chapel Pill Lane
Pill, Bristol
BS20 0HH**

Book by phone: 01243 572990 or online
Full programme of speakers will be sent out to member groups
and published on our website when available

www.prostatecancerfederation.org.uk/agm_2010.htm

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The Great PSA Debate – November 10th 2009, Leamington Spa

Over a hundred representatives of prostate cancer patient support groups went to **Leamington Spa** on 10th November 2009 to join with six distinguished experts in The Great PSA Debate, organised by the Prostate Cancer Support Federation and sponsored by the Graham Fulford Charitable Trust and Prostate UK.

Background

When it comes to PSA Testing, the general views of patients are completely at odds with those of many ‘professionals’. Patients, almost to a man, are in favour of universal testing, as it might lead to early detection and hence cure of many of the cancers currently detected late, when incurable. Health professionals generally have a much more sceptical view. Possibly because of very different agendas, those presenting the arguments on both sides are often talking past each other.

We needed a forum in which those on each side of the argument could talk intelligently to each other, and look for where consensus might be found. Above all, the aim of the day was to get the prostate cancer charities to speak with one voice on the issue. The wording of the motion was carefully chosen, avoiding the topic of formal screening, as it was clear that there was not the remotest chance of agreement on that. Instead, it concentrated on the idea that men should be encouraged to monitor their PSA levels. It was: *“Every man at risk of prostate disease ... should be encouraged to check his PSA every year.”*

Invited speakers

Before the debate proper, the scene was set by Dr Dennis Brennan, a recently retired company doctor, who illustrated the difficulties GPs face in deciding how to respond to men asking for the test. He represented the people who have to be convinced by the arguments of the debate.

Mr David Baxter-Smith, consultant urologist of many years experience who has conducted sessions of PSA Testing throughout the country and is the Federation’s medical advisor, opened the debate for the motion. He reminded the audience that when he started practice, very often the first symptom of prostate cancer would be one of the effects of bone metastasis, e.g. paralysis resulting from spinal damage. The discovery of PSA as a marker, however flawed, radically changed the way prostate cancer is managed. He made the point that over-treatment, which is acknowledged, is not the ‘fault’ of the PSA Test, but of the protocols

that attach to its use, in particular automatic biopsy and treatment of men with a PSA above a notional threshold. He emphasised that it is a test that we must use until something better comes along.

Ken Muir, Professor of epidemiology at Warwick University, then spoke against the motion. He played an intriguing ‘parlour’ game with the audience to show how the potential benefits of the test affect a very small proportion of society whilst the potential harms, due to the side-effects of unnecessary treatment, affect a very large proportion. He suggested that, whilst the argument about testing will rage on and on, a better way to spend our time would be to look at ways to prevent the disease.

Professor Roger Kirby, a urological surgeon, and Chairman of Trustees of Prostate UK, resumed the case for the motion. He outlined the obvious benefits of a man knowing his PSA and, as a counter to the over-treatment argument, proposed a more



Voting at the debate

sophisticated screening strategy: identify at risk groups and monitor their PSA kinetics. In such a regime one would look at risk factors (e.g. genetic risks) first, then screen if appropriate, backing up the basic PSA screening test with other tests, e.g. PCA3 and genetic markers.

John Neate, Chief Executive of The Prostate Cancer Charity, speaking against the motion, reviewed the Charity's research into patients', GPs' and the general public's attitude to PSA testing. The Charity supports the right of every man over 50 and those at higher risk – to make an informed choice about the PSA test, but it does not believe that a national screening programme would offer an acceptable balance between benefit and harm. It will work with the UK National Screening Committee (NSC) to bring the vital perspectives of men to their decision making process and, crucially, if the NSC recommends against screening, the Charity will lobby for alternative arrangements, e.g. through routine 'well man' health checks.

Dr Tom Stuttaford, prostate cancer patient and the political and media advisor for the Federation, who is well known to readers of *The Times* and *The Oldie*, spoke next. He made a comparison with other screening programmes, where, on similar evidence, screening has been adopted. He knew, from his time as an MP, that there is strong political pressure against screening, and that mortality figures have for some time been 'fixed'. The Treasury always rules, but the financial arguments don't stand up – early detection would undoubtedly save money.

Dr Chris Parker, our final speaker, oncologist from the Royal Marsden, explained his own personal view, which forces him to reject the motion. He prefers to accept a small increase in risk of death through not knowing his PSA rather than the very much larger increase of risk of unnecessary treatment. He illustrated graphically how the recent European trial had showed a 20% reduction in mortality, but at expense of massive over-treatment. He outlined a number of other risk factors that would be more effective than a screening programme in reducing death through early detection.

Open debate

As might be expected, the open debate session was lively and views were passionately expressed. However, it began to emerge that the two sides of the argument were actually much closer than had been thought. In particular, there was agreement by all that

1. men should be aware of the PSA test, its benefits and limitations, and of their right to have it;
2. GPs need education;
3. research is urgently needed to identify and get consensus on how to use risk factors to govern follow-up action.

Indeed, on a final vote in which the wording was changed to read *"Every man at risk of prostate disease ... should be made aware of the PSA test, its benefits and limitations and should be able to freely exercise his right to have it"*, there was total agreement, with a single abstention – a major achievement. For the first time, the

major charities are agreed on a policy for awareness raising about the availability of PSA testing for all men at risk.

Follow-up

Two streams of work have been identified. First, we must build on the consensus that men should be made aware of the test. The Prostate Cancer Charity are taking the lead on this, and we, in the Federation, are involved in their work. Our goal is to ensure that the NSC reflects this in whatever recommendations it makes about prostate cancer screening in the Spring.

Secondly, the risk assessment approach needs to be developed further. Prostate UK have offered to take the lead on this and we look forward to some early results.

Three months after the event, the 'buzz' that was reported around Leamington Spa station that evening has abated somewhat, and already there are frustrations that not much seems to be happening. It is still early days, but we, the Federation will keep the pressure on. An update on both these issues will be given at the Annual Conference on 24th April.

Sandy Tyndale-Biscoe
Chairman PCSF

Federation 'Real PCRMP' leaflets

As the Department of Health has now issued revised guidelines to GPs on PSA testing, we have updated and re-printed our own guideline sheet to distribute to GPs. If your group would like a further supply of these leaflets, contact 0161 474 8222

Prostate Cancer and Diet Update

NHS Choices recently reviewed prostate cancer¹. This was following the June 2009 publication of *Healthy Eating: The Prostate Care Cookbook*, which was produced in association with the Prostate Cancer Research Foundation. Prostate cancer is the most common cancer in men in the UK – it accounts for nearly a quarter (24%) of all new male cancer diagnoses. The lifetime risk of being diagnosed with prostate cancer is 1 in 10 for men in the UK².

World Cancer Research Fund says we all make lifestyle choices every day and there is overwhelming evidence that the choices we make can make a big difference to our cancer risk³. Cancer Research UK⁴ and NHS Choices¹ have made the following comments about diet and prostate cancer:

Countries that have a low fat and high vegetable intake in the diet have lower rates of prostate cancer. However, it is not certain whether this is directly due to fat intake. Studies are ongoing.

Lycopenes are chemicals found in tomatoes and may help to prevent prostate cancer. It is noted some studies of lycopenes and prostate cancer have shown a reduction in risk but others have not.

Dairy products, as a source of calcium, have been extensively studied in relation to prostate cancer. Several studies show a small significant increase in risk, but findings differ by whether it affects advanced or localised tumours. The EPIC⁵ study showed overall a 32% increased risk for 35g/day higher intake of dairy protein and a 7% risk increase for a 0.3g/day intake of dairy calcium. Protein and calcium from non-dairy sources were not associated with risk.

Countries that have a high intake of soy in their diet tend to have much lower rates of prostate cancer (and other types of cancers) compared to countries

where soy intake is low. This may be because of chemicals found in soy called phyto-oestrogens.

Several studies have shown a protective association for selenium, reporting a 30–80% risk reduction for prostate cancer. However, several studies showed no association.

Green tea has been studied due to its regular consumption by Japanese and Chinese men whose prostate cancer risk is low. Green tea contains high level of polyphenols which have anti-oxidant effects. The evidence is not conclusive. More research into the possible chemo-preventive properties of green tea is needed.

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Confirming the message of Cancer Research UK and NHS Choices, a 2009 systematic review of studies on soya consumption⁶ suggested that consumption of soya foods is associated with a reduction in prostate cancer risk in men.

A large study in the United States⁷ examined the associations between meat consumption and prostate cancer. “Red and processed meat may be positively associated

with prostate cancer” was the study conclusion.

There has also been research looking at diet and survival after prostate cancer diagnosis⁸. This showed that adoption of a plant-based diet may slow disease progression and improve prognosis. However the authors commented that additional long-term therapeutic clinical trials are needed to further elucidate the role of diet.

1. NHS Choices. Prostate Cancer-Cookbook:
<http://www.nhs.uk/news/2009/09september/pages/prostatecancercookbook.aspx> (accessed 23 October 2009)

2. Cancer Research UK. UK Prostate Cancer incidence statistics:
<http://info.cancerresearchuk.org/cancerstats/types/prostate/incidence/> (accessed 23 October 2009)

3. World Cancer Research Fund. The Choices that affect your cancer risk.
http://www.wcrf-uk.org/preventing_cancer/diet/choices_that_affect.php (accessed 23 October 2009)

4. Cancer Research UK. Prostate Cancer risk factors:
<http://info.cancerresearchuk.org/cancerstats/types/prostate/riskfactors/?a=5441> (accessed 23 October 2009)

5. Allen NE. *Key TJ*. et al. Animal foods, protein, calcium and prostate cancer risk: the European Prospective Investigation into Cancer and Nutrition. *British Journal of Cancer* 2008; 98(9): 1574-81.

6. Yan L. & Spitznagel EL. Soy consumption and prostate cancer risk in men: a revisit of a meta-analysis. *American Journal of Clinical Nutrition* 2009; 89: 1155-63.

7. Sinha R. Park Y. et al. Meat and Meat-related Compounds and Risk of Prostate Cancer in a Large Prospective Cohort Study in the United States *American Journal of Epidemiology* 2009; 170(9): 1165-1177

8. Berkow S. Barnard ND. et al. Diet and survival after prostate cancer diagnosis. *Nutrition Reviews* 2007; 65-9: 391-493.

Article written by Dr Philip Bickley
Published in 'The Vegan' winter 2009
www.vegansociety.com

The role of diet

Evidence clearly points to diet being a significant factor in development of cancer. Several instances have been reported of increased prostate cancer in populations that have switched from their traditional diet to Western-style foods; and although there is much more to be learned on this topic, we can be fairly certain from research findings that those who consume a diet rich in meat and dairy have a higher incidence of prostate cancer than those who don't.

On a more positive note, there is much talk now about how your diet and lifestyle, and in particular some specific food groups, can delay or even possibly prevent cancer. Here are a couple of examples.

The Prostate Care Cookbook

Launched in June 2009, the Prostate Care Cookbook is dedicated to foods that sustain prostate health. Working with Prof. Margaret Rayman and her team at the University of Surrey we have pulled together all the very latest thinking on the effectiveness of different foods, and Prof Rayman's team have written some imaginative recipes to get these into your daily eating regime.

The RRP is £12.99 or you can order the cookbook online via Amazon at a discounted price. Publisher: Kyle Books, 2009 ISBN 1906868042, 9781906868048.

Would you like to help with our research? Researchers at the Food, Consumer Behaviour and Health Research Centre at the University of Surrey are

interested in your views on food, prostate health and how you view a cookbook on Prostate Cancer. Please log on to their website and complete a short questionnaire.

Pomegranates

The BBC reported in September 2005 on research suggesting that pomegranate juice may help slow down the progress of prostate cancer.

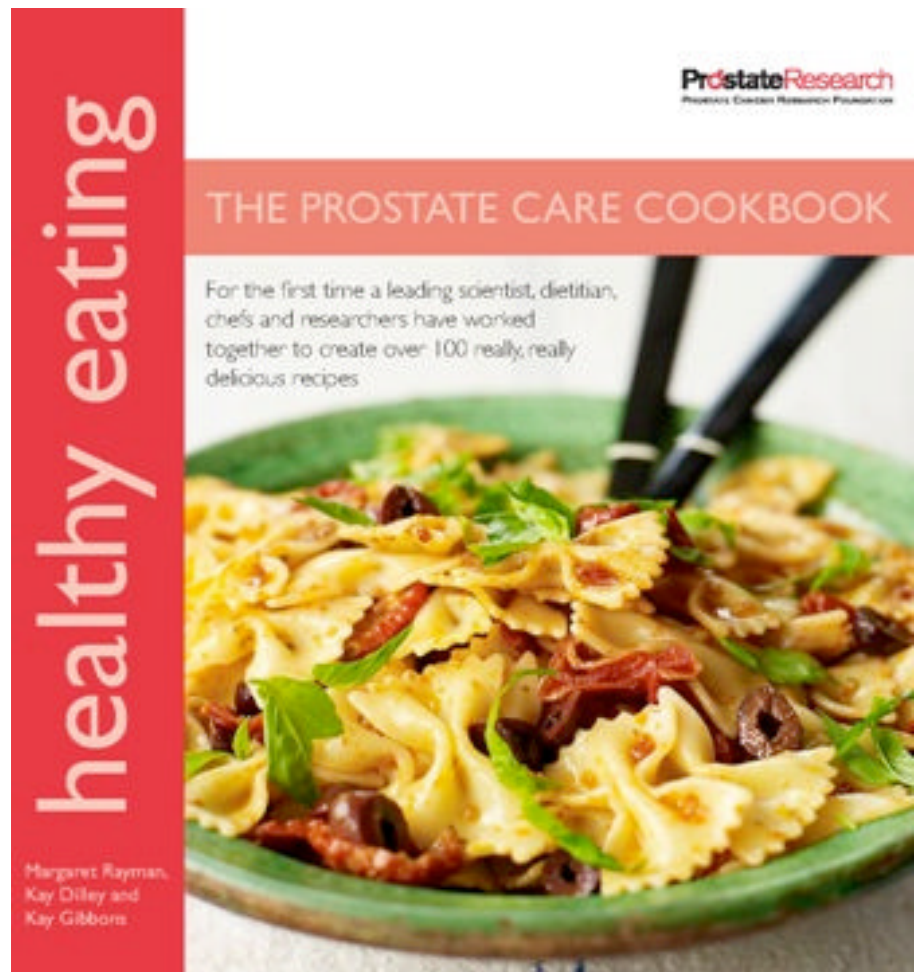
We were fortunate to have the support of *POM Wonderful* at our 2008 Gala Dinner, who donated bottles of their pomegranate juice for every attendee. Research using *POM Wonderful* undertaken by retired PCRF Trustee Arie Belldegrun at UCLA has suggested that drinking

pomegranate juice can delay PSA doubling time.

Vitamin D

There has also been research that suggests that sunlight can help reduce the risk of prostate cancer. It is thought that the body's manufacture of Vitamin D which is produced after exposure to sunlight helps protect the prostate.

**Prostate Cancer
Research
Foundation**
1st Floor,
1-3 Worship Street,
London EC2A 2AB
Telephone:
020 7330 0990.



RADICALS Clinical Trial

Radiotherapy and Androgen Deprivation In Combination After Local Surgery

RADICALS is a large clinical trial which is taking place in the UK and Canada. It will recruit around 4000 men to help answer two important questions for men who have had surgery for prostate cancer:

- When should radiotherapy be used after surgery?
- Should hormone treatment be used with radiotherapy after surgery?

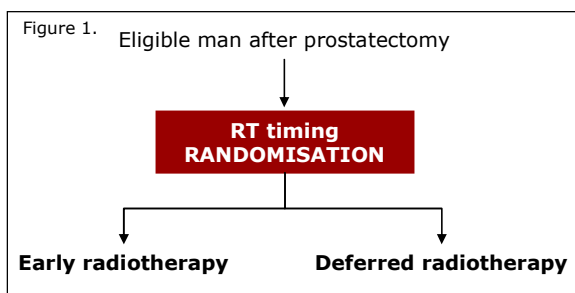
There are 2 parts to the study: **Radiotherapy Timing Comparison**(Fig. 1) & **Hormone Duration Comparison**(Fig. 2)

Radiotherapy Timing Comparison

This comparison is suitable for men who have had surgery for prostate cancer within the past 5 months, and who have at least one of the following 5 risk factors for recurrence (initial PSA > 10, Gleason score 7-10, positive margins, extra-capsular extension, or seminal vesicle involvement).

In the UK, radiotherapy is usually given after surgery if and when the PSA level starts to rise (deferred radiotherapy). An alternative approach is to use radiotherapy in all men within 6 months after surgery (early radiotherapy). Early radiotherapy might prevent the cancer from coming back but might also bring unwanted side-effects. RADICALS is comparing these two approaches. To ensure we can make a fair comparison, men who choose to join the trial are divided at random into two groups:

- men in one group receive regular PSA monitoring after surgery. If their PSA starts to rise, even slightly, radiotherapy is given (deferred radiotherapy)
- men in the other group receive radiotherapy within 6 months after their operation (early radiotherapy)



Hormone Duration Comparison

This comparison is suitable for men who are due to have radiotherapy to the prostate bed at any time after surgery for prostate cancer.

When radiotherapy is used after surgery for prostate cancer, it can be given either alone or together with hormone therapy. Both approaches are commonly used in the UK. We do not know which is better and, if it is better to use hormone therapy, for how long it should be given. RADICALS tests whether men receiving radiotherapy after surgery also need hormone therapy.

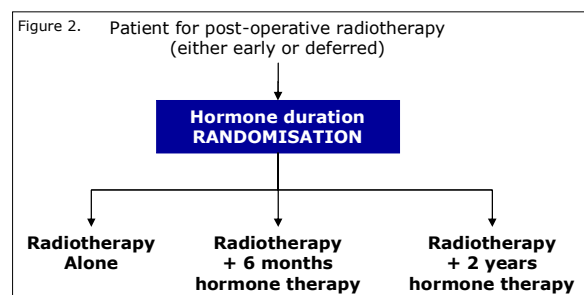
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In the Hormone Duration Comparison men who choose to join the trial are divided into three groups:

- Men in the first group will have radiotherapy alone
- Men in the second group will have radiotherapy and six months of hormone therapy
- Men in the third group will have radiotherapy and two years of hormone therapy



Hormone Duration Comparison

Around 400 patients have entered the trial so far. This is a good start, but nowhere near enough. Around 5,000 men have a radical prostatectomy every year in the UK. If just one in 5 of them were to take part in RADICALS, then we would complete recruitment in around 3 years.

What if the RADICALS trial is suitable for me

There are 67 hospitals throughout the UK that are participating in RADICALS. Your doctor should be able to provide you with information about the trial. If the study is suitable for you and you are interested in taking part, you will be given a patient information sheet. You will be asked to take it away with you so you have time to read and think about it.

STOP PRESS: Four patient representatives (well known to some of you!) have kindly helped to film a RADICALS Information Video. Available from your hospital or online via the website: www.ctu.mrc.ac.uk

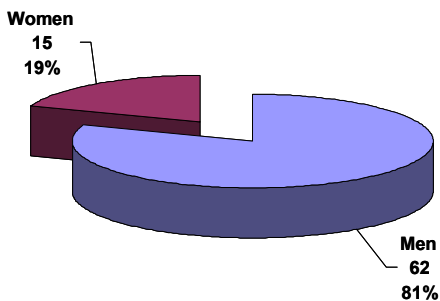
The Great PSA Debate Questionnaire Analysis Report

Introduction

On the 10th November 2009 at the Pump Rooms in Leamington Spa, the Great PSA Debate took place. To maximize debate findings a detailed questionnaire was completed by 75% of delegates. This report provides the findings and conclusions from this questionnaire.

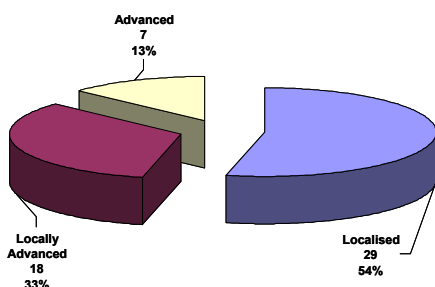
General Statistics

Delegates attending the debate numbered just less than 100 resulting in 77 delegates completing the questionnaire. The ages of male respondents ranged from one aged 27 and the remaining 61 being aged 54 to 78 years. The ages of female respondents ranged from one aged 26, one aged 43 and the remaining 13 being aged 60 to 73 years.

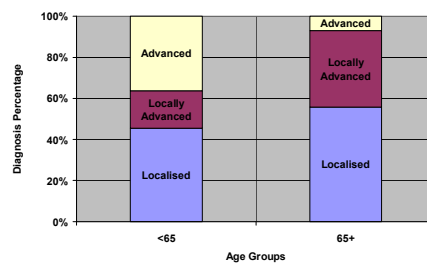


Prostate Cancer Diagnosis

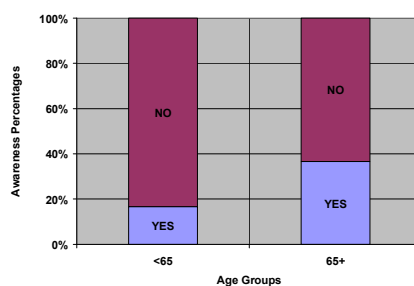
Prostate cancer sufferers were requested to indicate their stage at diagnosis by ticking boxes relating to localised, locally advanced and advanced prostate cancer. Just over half (54%) were diagnosed at a localised stage, benefiting from the greatest number of treatment options and the greatest possibility of a cure from the disease. Men diagnosed at a locally advanced stage represented 33% which meant they should have had a good chance of a cure but had less treatment options. Unfortunately, 13% were diagnosed with advanced prostate cancer.



The stage at diagnosis has been listed in two groups: those aged less than 65 (<65) and those aged 65 or older (65+). From the bar chart it can be seen in the <65 age group that approximately 45% of men were diagnosed at a localised stage, 19% were locally advanced and 36% at an advanced stage. As can be seen these results differ significantly with the 65+ age group where 56% were diagnosed localised, 38% locally advanced and 6% advanced stage.



A reason for these differences in diagnosis between the two age groups is attributed to lack of awareness of the symptoms as clearly indicated in the bar chart which shows that men in the 65+ age group are twice as aware as younger men in the <65 age group.

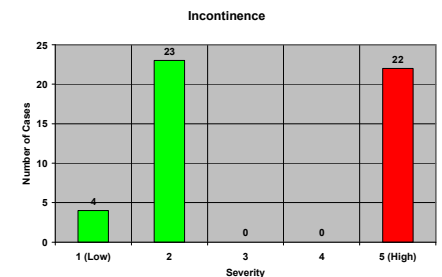


It can be concluded that younger men aged below 65 are at a greater risk of being diagnosed with prostate cancer at a locally advanced stage or at an incurable advanced stage because of ignorance (lack of awareness) of the symptoms and risks of prostate cancer.

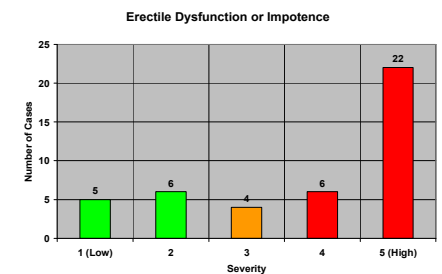
Treatment Complications

Respondents were asked to indicate if they suffered any complications from their treatment, to which 76% said yes and 24% said no. Respondents were also asked to indicate the type of complication and its severity with a score of 1 being low

and 5 being high. The severity of incontinence was high in nearly 45% of cases.



Erectile dysfunction or impotence complication cases have been grouped together. Again the severity of both was high, in approximately 65% of cases with a low incidence of erectile dysfunction or impotence in just over 11% of cases.



Severity was classified mid range for approximately 9% of cases. It must be noted that a serious complication of hormone suppression therapy is erectile dysfunction in the majority of case. As hormone therapy is the initial treatment for advanced prostate cancer sufferers, these cases should not be considered when assessing the impact of complications from traditional treatments such as Radical Prostatectomy and Radiotherapy, especially as these complications are often quoted as the consequence of over treatment brought about by no reliable diagnosis method to differentiate between the life threatening (tigers) and non life threatening (pussycats). Interestingly, treatment complications from Brachytherapy were reported to be low with no high severity complications being listed.

Thanks go to Doug Gray for putting the questionnaire together and producing the analysis. This is only part of a fuller 5 page report. For the full report email: dougray1@btinternet.com

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Prostate Matters is published four times a year. It provides news, information, personal memoir and opinion about prostate cancer. It also reports, quotes and cites published medical views and research findings about prostate problems. Anyone who wishes to embark on any dietary, drug, exercise or other lifestyle change intended to prevent or treat a specific disease or condition should first consult with and seek clearance from a qualified health care professional.

National Cancer Patient Information Pathways & Prescriptions

Background – The Department of Health (DH) white paper, “Our health, our care, our say” published in January 2006, made a commitment to improving access to appropriate information for people with health and social care needs. It stated: “we propose that services give all people with long-term health and social care needs and their carers an ‘information prescription’.

Information Prescriptions will be nationally recognised as a source of key information on services and care – seamlessly and formally integrated into the care process.

Identifying the need – the National Audit Office provided survey figures from 2004 showing

- 40% of cancer patients did not receive any information at the time they were diagnosed
- 20% did not receive information on discharge

Most lacked access to advice on financial benefits for support during illness

Target – to empower patients to fully understand their cancer and be involved in decision making and choices of care. Patients to have face to face communication with professionals and receive high quality tailored information at key points in their cancer journey, written in plain language. Information, stored online, will be given when needed at every point in the care pathway and patients and carers are able to ask for and choose what information to receive at every stage and in every encounter with a professional.

Collection of Information – all 30 cancer networks across England were asked to supply their local information pathway plans for the identified cancers. These were compared to identify commonality along with areas where little/no information is given out. Using web search, tumour specific charity information and general charity search, material was identified that could be used to support the mapped content for each cancer.

Delivering the Information – frontline cancer health professionals such as Clinical Nurse Specialists will be responsible for delivering to the patient *tailored information prescriptions*. Having identified what stage the patient’s cancer is, the CNS will access the web-based system so that the agreed patient information content can be selected and printed electronically to generate tailored personalised information prescriptions, given to the patient in a wallet. Additional printed booklet/leaflet information will also be available to the CNS to give to the patient.

The future – access to the system will be available at libraries, medical centres and dedicated clinics. It is hoped that eventually patients and their carers will be able to access their own personalised care programme by ‘logging-on’ to a secure area of the information website.

Now - the system goes ‘live’ in the spring 2010.

Roger Bacon

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