Prostate Cancer Foundation of Australia

PROSTATE HEIDELBERG - CANCER SUPPORT GROUP

Affiliated with the Prostate Cancer Foundation of Australia

Newsletter No: 108 **11th April 2012**

Prostate Heidelberg supports men with prostate cancer, and their families and carers. The support takes the form of shared experiences and knowledge from books, subscriptions and internet sites, and suggested help lines.

DISCLAIMER
Information contained in this newsletter or discussed at meetings, should not take the place of proper medical advice from a qualified health professional. The services of a qualified health practitioner should be sought before applying the information to particular circumstances. This disclaimer is issued without prejudice

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Annual subscription - $5

OUR CULTURE
1. Show respect to members and speakers;
2. Listen and allow people to speak;
3. Respect confidentiality;
4. Allow new ideas to be shared.

The Prostate Heidelberg Cancer Support Group last met on 11h April 2012 at the Ivanhoe Uniting Church Meeting Room at 10:00 am with 15 members in attendance.

Partners or carers are welcome to all meetings.

IT'S ALRIGHT TO GRIEVE
Amanda Pomery again visited the group and facilitated a discussion on grieving. It is an important part of the group that when someone dies, the members of the group grieve for the member who died, and also it can trigger grief resulting from previous personal losses. The group and Amanda, a psychologist, are trying to work out the best strategies and structures the group needs to support persons experiencing grief. We thank Amanda for her support. Her email is at the end of the Newsletter. The Steering Committee have a project to develop ways that the group can support families experiencing crisis or grief due to prostate cancer. Your ideas and feedback would be gratefully accepted.

PEER SUPPORT AT TIME OF DIAGNOSIS PROJECT
Prostate Heidelberg has so far sponsored a feasibility study which concluded that "peer support at time of diagnosis" is feasible (the next stage is a pilot). Also such peer support provides essential emotional support to patients and their families at a time of crisis - such emotional support not usually provided in hospitals and clinics.

A special reminder that we are celebrating our 10th birthday on Wednesday 11th July with a lunch at 12:30pm (immediately following our normal meeting). Banyule Council have donated the catering. Reserve the date for yourself and partners

***CALENDAR* 2012**
Meetings at Uniting Church Meeting Room, Seddon Street Ivanhoe at 10:00 am
- Wed 11th April 2012
- Wed 9th May 2012
  - "Tissue Research" Renea Taylor & Mitch Lawerence
- Wed 13th June 2012
- Wed 11th July 2012:
  - 10th Birthday celebration
- Wed 8th August 2012
- Wed 12th September 2012
  - "PSA, Prostate Markers" Ken Sikaris
- Wed 10th October 2012
- Wed 14th November 2012
  - "Erectile Dysfunction" Chris Love
- Wed 12th December 2012 followed by Xmas lunch

***CALENDAR* 2013**
- Wed 13th February 2013
- Wed 13th March 2013
- Wed 13th March 2013
- Wed 10th April 2013

Remember, the **PCFA's Localised Prostate Cancer Patient Pack** is available to newly diagnosed men from local pharmacies including nationally all ChemMart Pharmacies and Terry White Chemists. Ask your urologist for a voucher or contact Patrick Woodlock

Please contact Patrick Woodlock to redirect or cancel receipt of this Newsletter.

This month's speakers. - **Wed 9th May 2012**, We are pleased to have **Dr Renea Taylor** returning again to speak on **"Prostate Cancer Tissue Research"** and accompanied by fellow researcher **Dr Mitchell Lawrence.** This promises to be an interesting and stimulating presentation

Dr. Taylor obtained her PhD from Monash University in 2003 under the mentorship of Prof. Gail Risbridger. Renea has had an enormously productive and rewarding career. She is a mother of three beautiful children and despite these career interruptions has managed to reach some of the highest escalades for her career stage. Dr. Taylor has produced more than 26 peer reviewed publications in some of the most prestigious journal such as Nature Methods, PNAS, Stem Cells and Endocrinology. Her work has demonstrated directed differentiation of stem cells by prostatic stroma. Renea is member of the Australian Prostate Cancer Bio-Resource (APCC), Australian Society for Medical Research (ASMR) and contributes to numerous other professional scientific bodies. She has been awarded several prestigious prizes including the Distinguished Young Alumni Award from Monash University in 2008.

Dr Lawrence completed his PhD with Prof Judith Clements at the Australian Prostate Cancer Research Centre-Queensland, Queensland University of Technology. In 2010, he joined Monash University to work with Dr Caroline Gargett and Prof Gail Risbridger. Dr Lawrence is funded by an NH&MRC Early Career Fellowship and a Movember Young Investigator Grant awarded through Prostate Cancer Foundation of Australia's Research Program. The focus of Dr Lawrence's research is the tumour microenvironment, in particular defining the differences between normal prostate fibroblasts and cancer-associated fibroblasts.

THE PROSTATE CANCER DIAGNOSTIC JOURNEY

Your urologist/oncologist will finally recommend treatments after considering the following steps necessary to achieve a full diagnosis:

1. Digital Rectal Examination (DRE);
2. A prostate-specific antigen (PSA) blood test (a history of PSA tests is better than one test);
3. Biopsy (and resultant Gleason Score); and
4. Scans to determine staging.

DRE and PSA

The digital rectal examination is a doctor feeling for prostate hardness - an indicator of prostate cancer or, just as likely, a benign tumour. The PSA test is a key indicator of prostate tumour activity. A rising PSA (doubling in less than a 2 year period), is considered aggressive.

Biopsy and the Gleason Score

The DRE and PSA tests are relatively un-invasive (in hindsight). But they may lead the urologist to recommend a biopsy. The outcome of the biopsy is a Gleason Grading system (grading the prostate cancer based upon its microscopic appearance extracted in a biopsy) which is incorporated into a strategy of prostate cancer staging which predicts prognosis and helps guide therapy. Cancers with a higher Gleason score are more aggressive and have a worse prognosis.

The pathologist assigns a grade to the most common tumour pattern (the "primary" grade, representing the majority of tumour), and a second grade to the next most common tumour pattern (the "secondary" grade, relating to the minority of the tumour observed). The two grades are added together to get a Gleason Score. For example, if the most common tumour pattern was grade 3, and the next most common tumour pattern was grade 4, the Gleason Score would be 3+4 = 7. The Gleason Grade ranges from 1 to 5, with 5 having the worst prognosis. The Gleason Score ranges from 2 to 10, with 10 having the worst prognosis. For Gleason Score 7, a Gleason 4+3 is a more aggressive cancer than a Gleason 3+4.

http://en.wikipedia.org/wiki/Gleason_Grading_System

Staging of your cancer

After prostate cancer has been diagnosed, tests are done to find out if cancer cells have spread within the prostate or to other parts of the body. This is called staging. It is important to know the stage in order to plan treatment. The following stages are used for prostate cancer:

Stage I cancer is found in the prostate only.

Stage II cancer is more advanced than in stage I, but has not spread outside the prostate.

Stage III cancer has spread beyond the outer layer of the prostate on one or both sides and may have spread to the seminal vesicles, from where most of a man's semen comes.

Stage IV cancer has spread to any of the seminal vesicles, nearby tissue or organs, such as the rectum, bladder, or pelvic wall; nearby lymph nodes; has spread to distant parts of the body, maybe including lymph nodes or bones.

http://www.cancer.gov/cancertopics/pdq/treatment/prostate/Patient/page2#Keypoint8

Get the reports and PSA tests in writing

When you are diagnosed with prostate cancer, it is highly recommended you get a hard copy of the pathology reports, scans and the blood tests. These records give you a way to get back some control of your life. The records give you a journal and help you understand the urologists recommended treatments. Don't be afraid to ask your urologist to explain the recommendations to you and to provide you the recommendations and the possible side-effects in writing. It is very hard to understand an area of medicine to which you are a beginner, as well as a victim.

THE PROSTATE CANCER TREATMENT OPTIONS

Your urologist/oncologist will consider the results of the above tests, and also consider your age, your general health, and your family history. This will make your prostate cancer journey a journey unique to you. But you will be on pathways shared by others in their cancer journey. This means that someone you know may have what you think a similar disease; but to your urologist that cases are completely different.

A support group can provide you with help in understanding the urologist's recommendations. The urologist is rightly focusing on your medical issues. A support group can put you in touch with needed emotional support for you and your family.

The following treatments may be used in isolation, together with other treatments, and in varying order.

1. **No treatment** (watchful waiting) – possibly a slightly greater risk of cancer spreading during waiting period.
2. **Active Surveillance** – also possibly a slightly greater risk of cancer spreading during surveillance period.
3. **Surgery** – over 80% chance of survival (not dying) for 15 years if localised at the time of the surgery; but the side effects may include erectile dysfunction, impotence, urinary incontinence and penile shrinkage.
4. **Radiotherapy** – possibly both types (external beam and brachytherapy) can cure localised prostate cancer. It can be successfully used in combination with surgery and/or androgen deprivation therapy. There are similar survival rates as surgery. There is a risk of short term side effects, such as vomiting and nausea. The long term side effects may include infertility, rectal bleeding and incontinence, and secondary cancers (a low risk).
5. **Chemotherapy** - usually in the later stages.
6. **Androgen deprivation therapy** (hormone therapy). The usually reversible chemical (medicine) method uses drugs which act through the brain (called luteinising hormone releasing hormone (LRLH antagonists) to prevent the release of a hormone that causes the testicles to produce androgens (male hormones) such as testosterone. The surgical method removes the testicles. Side-effects may include hot flushes, breast enlargement, erectile dysfunction, weight gain, mood changes, osteoporosis and other un-pleasantries.

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1. **Focal therapy** is discussed later in the Newsletter but is still mostly in the research stages.
2. **Complementary therapies** are treatments that are medically accepted to work with the above treatment to mitigate the side-effects and help with your general well-being.
3. **Alternative therapies** are not medically proven. No alternative therapy has been proven to cure cancer.

Each option has effects and side-effects that may or may not apply to you. Discuss these with your doctor.

extracts from Localised Cancer Pack

LIBRARY SNIPPETS

From the PCFA, the Cancer Council and other expert organisations, the library includes books, pamphlets and DVDs on topics such as advanced or localised prostate cancer, treatments, incontinence, sexual dysfunction, diet and health, and a myriad of other titles. We encourage borrowers to return books, but we recognise that an important part of support is information dissemination – if you like the book, let us know and we'll see if we can get a copy for you. If you borrow material you found useful, let us know so others can share your enlightenment.

A new edition of "**The Essence of Health – the Seven Pillars of Wellbeing**" by Monash University's Dr Craig Hassed has been added to the library. The book brings together the very best of evidence-based, holistic medicine in a program that the reader can put into practice in daily life.

Our library includes several regular newsletters, which contain up to date news and information on prostate cancer from the United States. For example:

"**US TOO Prostate Cancer Education & Support HOTSHEET**", published in Illinois. The March 2012 issue includes articles "MDV 3100 in Prostate Cancer Impressive"; "Bone Metastases Target of New Agent"; "Benefits of Xgeva Don't Outweigh Risks"; "Finsteride Combo Reduces Recurring PSA".

"**PCRI Insights New Developments in Prostate Cancer Treatment**", published by Prostate Cancer Research Institute California. The February 2012 issue includes: "Indigo: The Fourth Shade" by Mark Scholz, MD - an overview of treatment and management options for men in the "fourth shade"; "Prostate Brachytherapy" by Peter Grimm, MD, answering some common questions about seed implants; "Oligometastatic Prostate Cancer" by Charles "Snuffy" Myers, MD, Michaels Dattoli, MD and Stephen M. Bravo, MD, an essay outlining the concept of oligometastatic disease. Report: 2011 NIH Active Surveillance Meeting in Washington, D.C. by Charles "Snuffy" Myers, MD; "Empowerment Without Medical Advice" by Jan Manarite, Senior Educational Facilitator.

FOCAL THERAPY AND IMAGE-GUIDED FOCAL THERAPY FOR PROSTATE CANCER

Focal therapy for prostate cancer has been an area of increased interest over the past decade. This provides a "fourth pathway" to treat prostate cancer, in addition to the accepted mainstays of surgery, radiation and hormonal/medical therapy. The premise behind focal therapy is to treat just the prostate for patients in whom no local or distant spread of disease is suspected. This is based on the same clinical criteria for standard risk stratification, and includes PSA, physical exam findings and biopsy results. Three methods are currently used for focal therapy.

1. **High-intensity focused ultrasound** (HIFU) is where an ultrasound transducer, similar to that used for medical scanning, deposits focused high-intensity sound waves which heat and cause cells in the tissue to expand and contract rapidly, damaging their integrity.
2. **Cryotherapy**, or freezing, is performed with a hollow needle, the tip of which is cooled with liquid nitrogen or another agent (such as argon gas). Just like a can of soda in the freezer will explode as the ice enlarges, so burst the cells in the frozen tissue.

3. P**hotodynamic** therapy uses a photosensitizer, a chemical agent which makes tissue exquisitely sensitive to specific wavelengths of light, combined with fiber optic catheters inserted into the prostate. This is still experimental, but promising.

The Bottom Line: as we detect prostate cancer earlier at lower aggressiveness, it becomes harder to justify the risks of surgery and radiation therapy, even though technological improvements are also reducing these risks. Focal therapy and image-guided therapy may provide an alternative for carefully selected candidates, although this **field is still quite young**, and **many treatments are still considered experimental**.
Prostate Cancer Research Institute 15th March 2012
http://www.prostate-cancer.org/pcricms/sites/default/files/PDFs/weekly-2-3.pdf

NEW DATA ON ASPIRIN'S ANTI-CANCER EFFECTS
Long-term, daily intake of aspirin can prevent and potentially treat cancer, three new research papers suggest, triggering calls to broaden recommendations for the drug's use. The series of UK papers published in the Lancet Wednesday add to the mounting evidence that the vascular and anti-cancer benefits of aspirin outweighed the harms of major bleeding.

In the first study of 51 patients, the cancer benefit became most apparent after five years of aspirin use, with patients experiencing a 37% reduced risk of cancer death from five years and onwards, compared with controls.

The second study on cancer metastasis (spread to other parts of the body) among almost 1000 patients with a new solid cancer diagnosis. Patients randomised to receive aspirin faced a 36% reduced risk of cancer with distant metastasis, a 46% reduced risk of a cancer in glandular tissue, and 18% reduced risk of other solid cancers compared with controls, the study found. "Future guidelines can no longer consider the use of aspirin for the prevention of vascular disease in isolation from cancer prevention," they said.
By Nyssa Skilton - Australian Doctor, "Australia's leading independent publication for GPs"
http://www.australiandoctor.com.au/news/latest-news/new-data-on-aspirin-s-anti-cancer-effects

QUESTION & ANSWERS
WHY CAN I GET A PSA READING AFTER I'VE HAD THE PROSTATE REMOVED?
The really simple answer is that you can. The PSA is a measure of the levels of protein in your blood called prostate-specific antigens. These cells are made by normal prostate cells as well as prostate cancer cells. After the removal of the prostate by surgery, the PSA reading usually indicates prostate cancer activity. Your urologist may recommend further tests to confirm, and/or anti-hormone medicines (or another appropriate treatment) to see if the PSA drops.

PREPARING FOR THE LAST ACT OF LIVING
A member joked in the last meeting that "life is a sexually transmitted disease that is always fatal." A characteristic shared by about all who are told they "have cancer" is being confronted by their own mortality. Prostate cancer is usually the "good" cancer in that its progression is measured in years and not months, and if diagnosed early enough, it can often be cured.

This means we can use the fear created by the diagnosis to get our affairs in order. The simple things we should consider now (and not leave until everyone is stressed out of their minds), is preparing a **will**, a **general (or financial) enduring power of attorney** and a **medical enduring power of attorney**. We should also consider **organ donation** as in most cases the cancer will not have moved from the pelvic seat.

At your local library is the Law Handbook. It is available for purchase from the Fitzroy Legal Service, who also has the handbook at http://www.lawhandbook.org.au/handbook/bk01-toc.php.

Your library will also have books on organ donation. A website with all the information you require is http://www.donatelife.gov.au.

UPCOMING EVENTS and SPEAKERS CONFIRMED;
Wed 11th July, 12:30pm – 2:30pm **Prostate Heidelberg's 10th birthday** with City of Banyule's Mayor, Tom Melican, as our guest speaker.

Wed 12th September, **Dr Ken Sikaris**, Director of Chemical Pathology, Melbourne Pathology.
Topic: "How to interpret PSA and the latest developments in Prostate markers"

Wed 14th November, **Dr Chris Love**, Specialist in Urological Prosthetics, Bayside Urology.
Topic: "Erectile Dysfunction"

NEXT MEETING: 10:00 am to 12.30 pm, Wednesday 9th May 2012 at the Ivanhoe Uniting Church Meeting Room, Seddon Street Ivanhoe (Melways 31 F8) – behind the Commonwealth Bank in Upper Heidelberg Rd.

CORRESPOND - Prostate Heidelberg, PO Box 241 Ivanhoe Vic 3079; ProstateHeidelberg@gmail.com

PCFA support group contact for Victoria and Tasmania is Amanda Pomery. Her email is amanda.pomery@pcfa.org.au.

SOME USEFUL PROSTATE WEBSITES

The internet provides general data; and therefore is best used as a way to form questions specific to your case that you can direct to your urologist.

Prostate Cancer Foundation of Australia www.pcfa.org.au;
USA Prostate Cancer Foundation www.pcf.org
Lions' Australian Prostate Cancer Collaboration www.prostatehealth.org.au;
National Cancer Institute: www.cancer.gov;
Cancer Council Victoria www.cancervic.org.au;
Continence Foundation of Australia www.continence.org.au;
Steve Dunn's Cancer Guide www.cancerguide.org;
Life Extension www.lef.org;
Us TOO International Prostate Cancer Education and Support Network www.prostatepointers.org
American Institute for Diseases of the Prostate www.prostateteam.com (Dr Charles "Snuffy" Myers)