



COMMITTEE:

Bob Cook, Treasurer
Chris Ellis
Spiros Haldas,
Max Shub, Facilitator
Peter Stanley
Patrick Woodlock, Convenor
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PO Box 241 Ivanhoe Vic 3079

Annual subscription - \$5

Meetings: 10:00am -12:30pm
Uniting Church Meeting Room
Seddon St, Ivanhoe

CALENDAR 2012

Wed 11th July 2012:
[10th Birthday celebration](#)

Wed 8th August 2012

[Healthy exercising](#)

[Neal Beachley](#)

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

Wed 8th May 2013

Wed 12th June 2012

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.

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, internet sites and 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.

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 13th June 2012 at the Ivanhoe Uniting Church Meeting Room at 10:00 am with 13 members in attendance.

Partners or carers are welcome to all meetings.

JULY'S MEETING IS OUR 10th BIRTHDAY

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). Please tell you friends. If you know past members, invite them as well.

RSVP: 4th July to prostateheidelberg@gmail.com or 9948 2070

WEB SITE

Max is continuing to develop www.prostateheidelberg.info, the group's own web-site. Any suggestions and comments you have, can be given to Max by phone or at the website. We hope this could be become an important tool to assist the support group in its endeavours.

MAINTAINING CONTACT WITH SICK MEMBERS

In the last meeting it was proposed that we contact sick members. If they want, members we can visit them. Neil Stewart volunteered to help establish the outreach support. But we need members (or their wives or partners) to contact us to let us know that visits would be welcome.



HISTORY OF PROSTATE HEIDELBERG

Prostate Heidelberg was started by Trevor Cottle back on the 10th July 2002. As well as living in the area, he was diagnosed and treated locally at the Heidelberg Repatriation Hospital. He felt that Heidelberg needed a local prostate cancer support group as there are private and public hospitals in the area providing treatment for prostate cancer patients.

Trevor had already started Prostate Geelong with Cyril Vosper (who passed away in 2004) from the idea developing from a senior citizens open day. Prostate Geelong still meets at the St John of God Hospital. Trevor and Cyril were a great team, having then started Prostate Melbourne at the Royal Melbourne Hospital.

Trevor's passion for a support group came to fruition at a meeting of Prostate Melbourne, where the Heidelberg locals agreed to meet separately. The inaugural meeting was assisted by local publicity. Trevor addressed Ivanhoe Rotary Club. He said if a venue could be found, a successful group could be formed. A member of Ivanhoe Rotary provided a meeting room at the local palliative care centre. Consequently, Prostate Heidelberg was formed.

The group out-grew the palliative care venue. Meetings were briefly moved to the Heidelberg RSL. Then, the more suitable - and current - accommodation was provided at the Ivanhoe Uniting Church's meeting room in Seddon Street. The group still meets there on the second Wednesday of each month (except January) at 10:00 am until 12:30 pm.

Each year in Australia, close to 3,300 men die of prostate cancer - equal to the number of women who die from breast cancer annually. Around 20,000 new cases are diagnosed in Australia every year.

Prostate cancer can be cured if detected and treated while still confined to the prostate gland. The tests for prostate cancer are the prostate specific antigen (PSA) blood test and the digital rectal examination (DRE). These tests do not give a conclusive diagnosis of cancer but can indicate the possible presence of prostate cancer.

The aim of Prostate Heidelberg is to offer men a place to meet. In the meetings, men, with their wives or partners, can gain information and, in discussion, share their experiences and views across the issues around prostate disease including prostate cancer, prostate enlargement, incontinence, impotence, erectile dysfunction, physiological issues, depression and other psychological issues, and other aspects associated with related complaints.

The group currently has 71 members on the mailing list. The monthly newsletter goes to about 150 subscribers. At the monthly meeting, attendees number between 12 and 25.

Prostate Heidelberg is currently operated through a steering committee consisting of Max Shub (Facilitator), Patrick Woodlock (Convenor), Bob Cook (Treasurer), Chris Ellis, Spiros Haldas, and Peter Stanley.

Prostate Heidelberg is indebted to its previous chairmen/convenors including Trevor Cottle, John Hook and Peter Stanley. Also since inception, the newsletters have been prepared and mailed by the Continence Foundation of Australia; we therefore acknowledge the support of Barry Cahill, the CEO, and Tina Addison, the worker.



QUESTIONS & ANSWERS

THE EMOTIONAL ISOLATION OF THE PROSTATE CANCER JOURNEY

The following comments are the opinion of the newsletter's author. A reference to a urologist/oncologist includes all the health professionals that know a person's case well enough to give specific comments.

Isolating Factors

When a person embarks on the prostate cancer journey, he should know that there are factors that will isolate him. These factors can be more emotional than the obvious medical and physical symptoms. He needs to be aware of these and take steps to talk about these factors from the medical, physical and emotional perspective. He needs to talk with his support network. The support network will include medical professionals, his family and friends, and the cancer support groups, which include peer support groups. The result of not talking about these factors is unhealthy. Without learning how to express his feelings as well as his symptoms, the man becomes isolated and stressed.

The isolating factors can include the following. Not all men will confront all of these factors. Some will breeze along the journey with no worries; and others will stumble over a few. But it gives comfort and hope to talk with others who have been through that step on the prostate cancer journey; therefore a peer support group can be helpful.

1. Incontinence;
2. Sexual Dysfunction
3. Impotence
4. Fear of Dying;
5. I've Lost Control of My Life
6. Cancer Pain
7. Chronic Fatigue
8. Guilt

Shared pathways on a unique journey.

Each person diagnosed with cancer will embark on a unique journey. But on that journey there are many shared pathways. Confronting the prostate cancer diagnosis, the advancing stages of the cancer (if not cured), the medications, the interventions (whether surgical, radiotherapy and/or chemotherapy), and the side effects of the medications and/or interventions is, at the very least, emotionally stressful. The man with prostate cancer can often find it hard to express his feelings, even to his wife or partner.

Urinary incontinence

Most people having any treatment will have pain and side-effects of some sort. But men with prostate cancer treatments often find the most difficulty with urinary incontinence (and also, the less common, bowel incontinence). Besides being something a man will have difficulty talking about, urinary incontinence is embarrassing socially. It isolates a man who cannot "control his bladder". It also is exhausting to be getting up a number of times each and every night. The thought of wetting their pants in public is terrifying. The first question, when you go out somewhere, is where's the nearest toilet and for how long does the outing go.

There are a number of medical solutions and exercises. The problem will often become more controlled over time.

Sexual dysfunction

Sexual dysfunction, when a man cannot "get it up", is also a factor that hits men emotionally and hard. He can feel "less of a man". Sometimes the dysfunction is temporary. Hormonal treatment



is designed to stop the production of testosterone, and is therefore described as “(reversible) chemical castration”. The problem needs to be dealt compassionately at the emotional level as well as the medical and physical levels.

Impotence

Impotence, where a man can no longer conceive children, is a side effect of a number of treatments and medications. It is not always a good idea to talk in terms of probability. It is no consolation to a man that he is in a select group when the consequences can be so dire. This is one area where a man needs to store his seed if this is an important matter to him.

Fear of Dying

When most men hear that they have prostate cancer, the immediate reaction is to think they will die from the cancer and soon. Rarely do people hear the rest of the diagnosis. This is a good reason to ask for the urologist to give you the report and recommendations (with options, if any) in writing. You might be reassured that, if you don't have Stage IV prostate cancer and Gleason Score 8 or greater (likely advanced cancer), you have a very small chance of dying from prostate cancer in the next 15 years. Even if you have advanced cancer, your survival rate is usually measured in years and not months. You can still plan for your future.

The thought that the cancer will “get you” becomes an “elephant in the room”, that you and others don't want to talk about. You can make it a small elephant, but rarely do men make it non-existent. It is an issue that needs to be talked about, because otherwise it does not go away.

Lost control

Commonly what also happens is the sense that you (and your wife/partner) have lost control of your life. You have to make choices about options about which you know nothing. Prostate cancer has a reputation as the cancer that takes a long time to develop, and also, the cancer where the treatment side-effects are possibly seen as worse than the cure. It is also common to ask your family and friends for advice. Unfortunately, your journey is unique. This means that advice given with the best intention may not apply in your case. The one you should talk to is your urologist/oncologist. Use the internet and your friends to formulate the questions to have your urologist/oncologist answer. The way to get some semblance of control of your new situation is by knowledge confirmed by your urologist.

Cancer Pain

It is common with advanced cancer to spread to the bone. This is painful. There are limited treatments. But seeking help with chronic pain specialists is recommended.

Chronic Fatigue

Having any cancer or chronic conditions gives fatigue. A man undergoing treatments will find that he cannot achieve as much in a day as he could. Cut back the expectations, but also exercise and lose weight. It is a legitimate side-effect of the cancer and therefore be not afraid to seek assistance.

Guilty of Looking Well

There are a number of times where guilt can come into play. Prostate cancer is a long journey. Friends and family, on the peripheral of the journey, sometimes can have unrealistic expectations for immediate results. The expected results can be that you are cured quickly; that you will die quickly; or that, because you haven't died, you are cured. It can be exhausting to explain yourself continually to those who do not know about the journey, particularly if you look healthy. There is no need to feel guilty. Have your own routine where you laugh later with your wife or partner. Maybe you can just say, “It's a long journey and I'm still on it. Thank you for your interest.”



Don't confuse experiences and medical opinions

The prostate cancer journey is one of emotional highs and lows. Support networks are essential. But the network is to support the man and his wife; it is not the advisors of what to do (the job of the urologist/oncologist). Most importantly the support network is to show some understanding and to be there for those on the journey.

PCFA UPDATE

John Friedsam, PCFA's Manager, Support Groups, has asked members (and particularly leaders) to be aware of four upcoming items:-

1. **Support Group Leader Survey**
Talking with leaders and others to assist PCFA in customising the type of support and training programs to be relevant and useful.
2. **Support Group Leader Survey - Study Opportunity**
Participate in a study entitled: "Understanding the Nature and Needs of Prostate Cancer Support Groups in Australia."
3. **Bunnings BBQ's**
PCFA have a corporate relationship with Bunnings. Each year (in September, to mark both International Prostate Cancer Awareness Month and Father's Day), Bunnings assists you in raising money specifically for your group's local use.
4. **PCFA's Big Aussie Barbie Campaign**
September is also PCFA's Big Aussie Barbie campaign month to coincide with International Prostate Cancer Awareness month. It is important to note that this Barbie campaign is different than the Bunnings BBQ's.

TRIAL MEETINGS AT NIGHT

It was agreed that we would trial a night meeting to attract members who cannot attend during the day. We are open to suggestions. October is the month for which we are aiming.

PBAC LISTING FOR ZYTIGA® (Abiraterone Acetate)

There is a proposal to obtain Pharmaceutical Benefits Advisory Committee (PBAC) listing for Zytiga (Abiraterone acetate), a 250 mg tablet, at the July meeting of PBAC.

In April 2011, Zytiga, in combination with prednisone, was approved in the USA for the treatment of men with advanced metastatic castration-resistant prostate cancer who have received prior chemotherapy containing docetaxel. (www.janssenrnd.com)

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 want to keep the book, let us know and we'll replace it for others to read. If you borrow material you found useful, let us know so others can share your enlightenment.



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**, our guest speaker.

Wed 8th August, **Neal Beachley** will present his healthy exercise regime and recommendations.

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 11th July 2012 at the Ivanhoe Uniting Church Meeting Room, Seddon Street Ivanhoe (Melways 31 F8) - behind the Commonwealth Bank in Upper Heidelberg Rd. The meeting is followed at 12:30 pm with Prostate Heidelberg's 10th birthday lunch.

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

USEFUL PROSTATE WEBSITES

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)