



THE WALNUT

August 2016

Newsletter of the Prostate Cancer Support Group - ACT Region Inc.

Affiliated with the Prostate Cancer Foundation of Australia



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Next monthly meeting

All are welcome to attend our regular monthly meetings, including partners and carers. No notice is required—simply come along and introduce yourself, or contact one of the people listed later in this newsletter.

Meetings of our support group are held on every **third Wednesday of the month** (except in December) at **6:30 pm for 7:00 pm**. The **usual location** is Room 22, Building 1, Pearce Community Centre, Collett Place, Pearce, ACT 2607. See our website here for details and map showing the location: <http://tinyurl.com/8gkhysb>.

Our next monthly meeting will be on **Wednesday, 17 August** at our usual location and time (see above). Our speaker will be Helen Tayler on the topic of 'Mindfulness', the role of mediation in recovery.

Helen Tayler will speak to members on mindfulness. Helen is Social Worker/Counsellor, Cancer Counselling Service, Belconnen Community Health Centre. She describes mindfulness as a tool kit to help us better manage the many impacts of cancer. At the meeting Helen will explain the meaning of mindfulness, demonstrate some practices and issue

pamphlets inviting people to her September/October clinics. She will bring some books about mindfulness for display and browsing interest on the night. Helen is well aware of the many stresses and tensions affecting us all. This is one of the many ways, along with diet and exercise, that we can help ourselves. There will be a question and answer session at the end of the talk. All men and women are welcome to attend the meeting - members, non-members, carers, friends and 'just interested'.

There will be plenty of time available at the meeting for current and new members to exchange information and to discuss matters of interest or concern.

Personal support

For general information, please call SHOUT (Self Help Organisations United Together), who will arrange for someone from the Group to contact you. They are available during normal office hours on (02) 6290 1984.

If you would like immediate advice, support or assistance, please contact any of the following people:

President: John McWilliam

Phone: 0416 008 299

Email: president@prostate-cancer-support-act.net

Secretary: David Hennessy

Phone: (02) 6154 4274

Email: secretary@prostate-cancer-support-act.net

President's report

Our Annual General Meeting in September is fast approaching. At that meeting, we will be electing your Executive Committee members for the coming year and, under general business following that meeting, we will be screening the PCFA webcast on *Prostate Cancer: Diet, Supplements and Lifestyle*.

On page 3, nominations are sought for the Executive Committee positions. To help assure the continued successful operation of the Support Group, we need

some volunteers to take on some of these roles. Please consider nominating for these roles. We urgently need your support with this. Other Executive Committee members will provide guidance in undertaking these roles.

Our Librarian and Resources Officer, UN Bhati, is currently having treatment in Melbourne following a recurrence of cancer, and we all hope that this goes well for him. We look forward to welcoming him back in September.

John McWilliam
President

Previous meetings

June General Meeting

Dr Lyn Austen's presentation attracted a lot of interest and many questions. It was highly informative. Her presentation covered the following three main topics: radiation; staging; and PSMA (Prostate Specific Membrane Antigen) scanning.

Radiation: Dr Austen explained what radiation oncology treatment involved. This began with a clinical appointment, at which baseline observations were made and X-rays and other test report results were collected. Other tests, an AUA (American Urological Association) urine test, might also be undertaken. The patient is initially seen by a registrar and then by the consultant. Radiation oncology treatment has improved considerably over recent years. Radiation treatment of prostate cancer is usually treated using brachytherapy. The positioning of the radioisotope 'seeds' (80 to 120 seeds for a low dose) is guided by CT scans. Low dose treatments brachytherapy are done in day surgery. High dose treatments are done over two days. External beam radiotherapy treatment (EBRT) has also improved. While once it was unavoidable that large healthy areas outside the prostate would also receive the radiotherapy, this is now considerably more contained, because the radiation beams are more targeted. A patient will usually have flatulence and, in the last two weeks, diarrhoea. Cancer nurse care consultants are available to support patients throughout the treatment.

Staging: Staging refers to how far a cancer has spread beyond the prostate, in particular the size and location of the tumours. There are four categories (with sub-categories within these four categories) for determining the local extent of a prostate tumour:

T1. The tumour or cancer cannot be felt by the doctor during examination

T2. The cancer can be felt but it has not spread outside of the prostate

T3. The cancer has spread outside of the prostate into nearby tissues

T4. The cancer has spread into nearby organs such as the bladder.

Assessment of staging is only as good as the available tests. As the tests improve, so the staging criteria or standards may change. Staging may also vary depending on the medical practitioners performing the test and there are different clinical, pathological and radiological staging standards.

Assessment of staging can pose numerous dilemmas, such as when to perform certain tests, particularly given their cost and the reliability of the tests (for example, performing a test at too early a stage may give a false negative result). Also, while treatment may be performed earlier, it is still too early to know whether this will result in a long-term improvement in survival rates.

PSMA scanning: PSMA testing enables the early detection and localisation of metastases for targeted radiation treatment and other therapy planning. Positron emission topography (PET) and computerised technology (CT) imaging tools allow physicians to pinpoint the location of cancer within the body before making treatment recommendations. PSMA PET-CT scans are able to detect small volume recurrent prostate carcinoma when there is a PSA rise after prostatectomy or other treatment for prostate cancer. There are several specific tracers now available, including Ga (Gallium) PSMA.

Unlike PSA tests, which only give results when there are dead cells, PSMA tests give results based on living cells. PSMA testing is not currently available in Canberra, but the Canberra Hospital does refer patients to Sydney (Nepean Hospital and St Vincent's Hospital) and Melbourne. PSMA tests are not covered by Medicare. Whether Canberra will get PSMA testing in the future is largely dependent on the demand for such tests. It may be more cost effective to continue sending patients to Sydney and Melbourne.

Because PSMA testing is relatively new, evaluation of the effectiveness of the scans is continuing. However, early studies have indicated that metastasized cancers can be picked up when a person's PSA reading is as low as 0.1. Nonetheless, generally, tests will not be undertaken unless a person has a PSA reading of at least 0.2. In a randomised trial of 37 patients, 85 per cent of the patients were detected as having metastasized cancers (see page 5).

Further information about radiation therapy is available at the following website: www.targetingcancer.com.au.



President, John McWilliam, and Dr Lyn Austen



Dr Lyn Austen speaking to Michael Fullam-Stone after the meeting

July Executive Meeting

At its August meeting, the Executive, among other things,:

- approved a records management strategy that will involve the digital storage of essential Group records in a central location;
- noted with appreciation that the Canberra Southern Cross Club has approved a grant of \$500 to the Group;
- noted that the Treasurer is arranging for the auditing of the Group's financial statements for 2015–16;
- noted arrangements for coming meetings, including the Annual General Meeting in

September and agreed to call for nominations for Executive Committee positions and matters of business to be considered at the AGM in this edition of the newsletter (see following two items); and

- considered arrangements for supporting coming outreach activities.

Nominations for Executive Committee positions

Nominations are sought for the Executive Committee following the Annual General Meeting in September. In particular, we know that John Lucas will be resigning as Treasurer after many years in the position. This is not an onerous position and John Lucas will provide a handover to the person taking over the role.

Allan Jackson will also be stepping down as organiser of the speakers at our meetings for health reasons. Allan will be a great loss as he has been doing a wonderful job. We need someone to step in and take on this role.

We would also like someone to volunteer to produce the newsletter. Currently John McWilliam is producing this in addition to his role as President. It would be good to have someone, who is prepared to take on this role, and so help to 'spread the load'.

Please consider nominating for one of these roles or other Executive Committee positions. We are dependent on you, our members, for our continued operation and the valuable role we play in supporting people with the health of their prostate.

Please contact John McWilliam or David Hennessy if you are willing to taken on one of these positions or would like to nominate for another position. Their contact details are on page 1 of the newsletter.

Matters for consideration at the Annual General Meeting in September

If any member has a matter that he or she wishes to raise at the AGM in September, please advise the Secretary, David Hennessy, secretary@prostate-cancer-support-act.net.

At the AGM in 2004, a motion was put to amend clause 15 of the Group's Constitution to limit the period of office of Executive Committee members to a period of no more than two years. A number of difficulties have emerged with this change:

- (i) 21 days notice of the change to the Constitution was not given, as required by clause 38;
- (ii) this change was not lodged with the Registrar, as required, and so has not come into effect; and
- (iii) no record appears to have been made of the change, and so the proposed change to the wording of the Constitution is not known.

Given this state of affairs and the fact that it has proved difficult to attract members to fill Executive member positions, it will be moved at the AGM that:

Changes agreed to clause 15 of the Constitution in September 2014 to limit the terms of members of the Executive Committee be declared null and void and the wording of that clause remain unchanged.

Men and sexual health—prostate cancer survey

One in three men have concerns about their sexual health after prostate cancer treatment. Many men are reluctant to get help for their sexual concerns, and when they do, often men do not continue with treatment.

There is little research to help us understand men's concerns about their sexual health after prostate cancer. The Prostate Cancer Foundation of Australia is working with Griffith University, the Cancer Council of Queensland, the Australian & New Zealand Urogenital and Prostate Cancer Trials Group and the Prostate Cancer Foundation of New Zealand to better understand men's sexual concerns after prostate cancer treatment and how we can best give men the help they need. As part of this, Griffith University is conducting an online survey to give men a chance to voice their concerns and preferences for support services in dealing with the effects of prostate cancer treatment on their sex life and overall quality of life. It is trying to reach out to as many men as possible to undertake the survey.

The survey takes 30 to 40 minutes to complete. In addition, if the respondent agrees, the researchers will contact the respondent again in 6 and 12 months to complete follow-up surveys.

If you are willing to participate in the study, please complete the survey at www.menandprostatecancer.org. Should you have any questions about the project, please contact the project manager, Ms Kirstyn Laurie on k.laurie@griffith.edu.au.

Previous work with support groups in Queensland showed that less than one-third of men sought help for their sexual concerns after prostate cancer treatment, and that men with severe erectile dysfunction were least likely to do so. A summary of this study is reprinted in the section on research articles on page 5.

Upcoming events

Big Boys Toys Expo: The Group will have an information table in the 'Big Boys Toys Expo' at Exhibition Park from 20 and 21 August.

September monthly meeting: September is our annual general meeting and will be followed by our normal monthly meeting. We will screen the PCFA webcast on *Prostate Cancer: Diet, Supplements and Lifestyle* at this meeting.

Self-help and Wellbeing Expo, 10 am to 3 pm, 21 September, Hellenic Club, Woden.

Murrumbateman Field Days: Information table in the marquee at the Murrumbateman Field Days, 15 and 16 October.

If you are able to provide a couple of hours of your time to support any of these activities, please advise Mark Jardine (zathraszero@gmail.com).

[Thanks to those who have already advised that they are willing to support the Big Boys Toys Expo. Mark will be in touch with you shortly.]

Appreciation

The Group acknowledges with appreciation the Canberra Southern Cross Club's advice that it will be making a grant of \$500 to help support the work of the Group. The Group relies on community funding to support its activities and this donation will be most helpful to us in doing this.

The Group notes that voting is currently taking place for the Club of the Year Awards. You may wish to consider voting for the Club in these awards and also have the opportunity to win a trip for two to Hamilton Island. To vote go to: <http://www.yourcanberraclubs.com.au/vote/>

Condolences

Sadly Roger Rose passed away on July 11th from his prostate cancer. We extend our sincerest condolences to Margaret and the family.

PCFA polo shirts for purchase

The PCFA is selling PCF-branded polo shirts to members. These come in blue and navy colours and cost \$23.95 each. If you would like to purchase a shirt, please let John Lucas know by Monday, 22 August.

Photos of the shirts and their sizes are attached to this newsletter.

Borrowing items from the Library

Don't forget that you can borrow items from the Group's Library. There is a wide range of materials, from books to videos. Those who are interested in borrowing items from the Library (such as the new *Cancer Recovery Guide* book that we have acquired) or finding out more about materials we have can contact U N Bhati email: unbhati@gmail.com.

Recent articles and reports that might be of interest

The following articles that have appeared recently on web sites or other sources may be of interest to some members. The group's Executive has not attempted to evaluate the articles' findings and conclusions or the credentials of the authors. Any opinions or conclusions expressed are those of the authors. Other medical practitioners or other practitioners may have other views. The articles are simply being drawn to your attention so that you can read them in full for yourself and make your own evaluation.

Comparison of PET imaging with a ⁶⁸Ga-labelled PSMA ligand and ¹⁸F-choline-based PET/CT for the diagnosis of recurrent prostate cancer

Ali Afshar-Oromieh, Christian M Zechmann, nna Malcher, Matthias Eder, Michael Eisenhut, Heinz G Linhard, Tim Holland-Letz, Boris A Hadaschik, Frederik L Giesel, Jürgen Debus and Uwe Haberkorn, European Journal of Nuclear Medicine and Molecular Imaging, Jan 2014, Vol 41, Issue 1, pp. 11-20.

This is the study referred to by Dr Lyn Austen in her talk at our July meeting.

The conclusion of the study was that ⁶⁸Ga-PSMA (Prostate Specific Membrane Antigen) PET/CT (Positron Emission Topography/Computerised Technology) can detect lesions characteristic for prostate cancer with improved contrast when compared to standard ¹⁸F-fluoromethylcholine, especially at low PSA levels. A total of 78 lesions

characteristic for prostate cancer were detected in 32 patients using ⁶⁸Ga-PSMA PET/CT and 56 lesions were detected in 26 patients using choline PET/CT. This difference in the two methods was statistically significant. In five patients no lesion was found with both methods.

The full article can be found at <http://tinyurl.com/jx6a583>.

Medical help-seeking for sexual concerns in prostate cancer survivors—pilot study

Hyde MK, Zajdlewicz L, Wootten AC, Nelson CJ, Lowe A, Dunn J, Chambers SK, Sexual Medicine, 2016; 4(1):e7–e17.

Approximately one-third of men have concerns about their sexual health after prostate cancer surgery, such as erectile dysfunction, according to a study undertaken by researchers at Griffith University in Queensland.

Men are often reluctant to seek help for these concerns and their decisions to do so are not well understood. 510 men who had been diagnosed with prostate cancer were surveyed by the researchers about their masculine beliefs, attitudes, support from their partner and peers, confidence, and their past and future decisions to seek help for erectile dysfunction. Survey results showed that 30% of men had sought help in the past. However, those with severe erectile dysfunction did so less frequently. 24% intended to seek help in the future. Men who intended to seek help in the future for erectile dysfunction were more emotionally self-reliant, placed greater importance on sex, and felt more supported by their personal, social and health professional networks. Overall, this study suggests that masculine beliefs (emotional self-reliance, importance of sex) may be a key driver of men's decisions to seek help for sexual concerns, and health professionals, partners and peers are a key source of support and encouragement. Other health professionals, such as nurses, sex therapists or counselors may also play an important role in sexual recovery and men's decisions to seek support from these providers should be considered in future research. As well, this study gave a snapshot of men's decision-making at one point in time. Their support needs and sexual concerns over time requires more investigation.

The abstract of the study is at: <http://tinyurl.com/j6wl670>.

Half of cancer deaths preventable with healthier lifestyle

Half of all cancer deaths and 20-40 per cent of cancer cases in the United States could potentially be prevented if individuals adopted healthier lifestyles, according to a study published in *The Journal of the American Medical Association, Oncology*.

“These findings reinforce the predominate importance of lifestyle factors in determining cancer risk,” wrote the study authors Mingyang Song, MD, ScD, and Edward Giovannucci, MD, ScD, of the Harvard T.H. Chan School of Public Health and Harvard Medical School in Boston. “Therefore, primary prevention should remain a priority for cancer control.”

An accompanying editorial expressed the opinion that “As a society, we need to avoid procrastination induced by thoughts that chance drives all cancer risk or that new medical discoveries are needed to make major gains against cancer, and instead we must embrace the opportunity to reduce our collective cancer toll by implementing effective prevention strategies and changing the way we live.”

Read the full article, published online on 19 May 2016 at <http://tinyurl.com/gm6v3vm>.

Obesity and a high-fat diet promote prostate cancer progression by amplifying the activity of cancer genes

At the 2016 Annual American Association for Cancer Research Conference, Giorgia Zadra, PhD, of the Harvard: Dana-Farber Cancer Institute and Brigham and Women's Hospital, presented results from a study that helped to clarify the relationship between obesity and prostate cancer. The study showed that fat increases the activity of MYC, the cancer-causing gene. It also indicated that a high-fat diet not only causes cancer but also speeds up prostate cancer progression.

Read full article on the website of Prostate Cancer Foundation, Santa Monica, CA 90401, USA
<http://tinyurl.com/jbxxv8u>.

PSA screening: don't throw the baby out with the bathwater

[Some experts claim PSA testing isn't useful, while others favour PSA testing of whole population. Read this news report if the debate interests you.]

Population-based prostate cancer screening remains decidedly controversial, especially after the US

Preventive Services Task Force recommended against routine prostate-specific antigen (PSA)-based prostate cancer screening for healthy men in 2012, regardless of age.

But prostate cancer experts have maintained that PSA testing is useful and that it reduces the risk for death — and this argument is made forcefully in a comments paper published online July 18, 2016 in the *Journal of Clinical Oncology* (JCO).

Jonathan E. Shoag, MD, from New York Presbyterian Hospital, New York City, and colleagues, argued that the evidence shows that PSA testing does reduce prostate cancer mortality, and they call for a return to screening, albeit not a population-wide annual PSA testing. Instead, they proposed that all men should undergo at least baseline PSA testing in their 40s or early 50s (except for individuals with a limited life expectancy). Subsequent screening after that would be tailored to individualised risk according ‘to schedules put forth in newer screening guidelines’.

Read full news report by Roxanne Nelson at <http://tinyurl.com/jz42hf8> on Medscape website <http://www.medscape.com> (requires free registration).

Managing depression in patients with cancer

The diagnosis and treatment of depression in the cancer setting can improve patients' quality of life, their adherence to therapy recommendations, and the illness experience, all of which may affect survival outcomes. In the past, the attitude toward the management of depression in patients with cancer originated from the idea that all cancer patients suffered from depression of some form, for which little could be done. There are now many effective treatments for depression in cancer patients. An oncologist can diagnose depression and initiate its treatment as a means to alleviate substantial suffering, contribute to better health outcomes and provide comprehensive patient-centred care.

Read full article at <http://tinyurl.com/h45psdn>.

From the editor

If you are aware of news, products, publications, web sites, services or events that may be of interest to members of the group I'd like to be informed of them. If you have received this newsletter indirectly and would like to be emailed a copy direct, or if you would like to add any of your friends or carers, or if you no longer wish to receive copies of the newsletter, please send me an email through the form here:

<http://tinyurl.com/grshy8s>.

Disclaimer

From time to time in our newsletters we provide information about developments in the diagnosis and treatment of prostate cancer, research articles, documents, audiovisual products, presentations and other interesting materials. However, the Group's Executive and the editor of this newsletter do not have the medical expertise required to make an informed evaluation of the conclusions and recommendations presented in such materials, and we have not verified such conclusions and recommendations through appropriately qualified medical professionals. The information presented in this newsletter must not be interpreted as being endorsed or recommended by the Executive or the editor. Any recommendations made in such materials may not be applicable in your particular case. Before implementing any recommendations made in the materials that are reported, it is essential that you obtain advice from appropriately qualified medical professionals. The view of the Group's Executive is that no two prostate cancer cases are alike and that no single treatment option is better than any other in all cases. While the information in this newsletter should be of interest, there is no substitute for getting informed medical advice from your own GP, specialists and other medical professionals.

The PCFA shirts for purchase



SHIRT 1



SHIRT 2

Men's Shirt	S	M	L	XL	XXL	3XL	5XL
½ Chest Measurement (cm)	53	55.5	58	60.5	63	68	73
High Point Shoulder to Hem (cm)	69	71	73	75	77	79	81

Ladies Shirt	6	8	10	12	14	16	18	20	22	24	26
½ Chest Measurement (cm)	42.5	45	47.5	50	52.5	55	57.5	60	64.5	69.5	74.5