



THE WALNUT

MAY 2019

Newsletter of the Prostate Cancer Support Group—ACT Region

Affiliated with the Prostate Cancer Foundation of Australia (PCFA)

Postal address: PO Box 650, Mawson ACT 2607

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Next monthly meeting

Our next monthly meeting will be held on **Wednesday 15 May 2019**.

There will be no external speaker at our May meeting. Instead there will be a discussion about various aspects of members' prostate cancer journeys.

All are welcome to attend our regular monthly meetings and coffee mornings, including partners and carers. No notice is required. Simply come along and introduce yourself, or contact one of the people listed on page 2 of this newsletter.

Meetings of our support group are held on the 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.

President's Message

David Hennessy and I attended a conference of the Combined Prostate Cancer Support Groups of NSW on the weekend of 4 and 5 May. The conference covered all the main aspects of the treatment of prostate cancer and it was most informative. The conference organisers, particularly Elizabeth Allen, did a fantastic job.

The conference was a great opportunity to meet members of other prostate cancer support groups and of the PCFA, including the new PCFA Chief Executive and Nikola Ellis, PCFA Director of Support and Community Outreach. All-in-all, it was a most enjoyable and worthwhile weekend. It is likely that the next conference will be held in two years' time and I encourage attendance. You will not be disappointed.

At the conference it was also announced that the 2019 Max Gardner Award has been awarded to Mary Jones from the Northern Beaches Prostate Cancer Support Group. Well deserved, Mary.

Those who attended our April meeting will have enjoyed the presentation provided by Dr Catherine Paterson. Dr Paterson's interest in pre-habilitation (in its widest sense to include ensuring that patients understand and are well prepared for post-operative recovery) is something that support group members will appreciate as being so valuable. For this reason, the Group has agreed to co-sponsor an application by Dr Paterson for a grant from the Rosemary Bryant Foundation to undertake research into whether a multimodal pre-habilitation intervention gives better functional and quality of life outcomes than usual care for men choosing prostatectomy for localised prostate cancer treatment.

John McWilliam

Appreciation

The Group recognises and expresses its appreciation for the support provided by: the PCFA, SHOUT staff, Harness Racing ACT, staff of the Australian Department of Human Services (Chief Technology Office), the Canberra Southern Cross Club, Holy Family School Gowrie, Paddywack Promotional Products, Residents' Social Club at The Grove, Ngunnawal and the many individuals who have assisted in our fund-raising activities over the past year.

Personal support

For general information, please call SHOUT (Self Help Organisations United Together) during normal office hours on (02) 6290 1984, and their staff will arrange for someone to contact you.

If you would like immediate advice, support or assistance, please contact one of the following two 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

Next Coffee morning

10:00 am, Tuesday, 14 May at the Canberra Southern Cross Club, Jamison.

Coffee mornings are held at 10:00 am on the second Tuesday of each month and alternate between the Woden and Jamison venues of the Canberra Southern Cross Club.



Our April meeting

Our speaker in April was Dr Catherine Paterson. Her talk focused on the need to be prepared for changes in life and function ability before treatment for prostate cancer.

Dr Paterson commenced her career in North-East Scotland as a registered nurse, working in neurology. Her interest in prostate cancer began with her contact with oil workers from the North Sea platforms, especially in observing the high rate of end-stage prostate cancer in the workers. She then undertook post-doctoral studies and has published studies on men's reaction to prostate cancer, and on how to better prepare men for the after-effects of treatment. With others she established the concept of 'pre-habilitation', which is the continuum of care between diagnosis and the beginning of acute treatment. This care includes nutrition, exercise physiology, counselling and other aspects relating to well-being and self-worth.

In a 2018 study in Scotland, Dr Paterson and her fellow researchers set out to determine the effectiveness of a multimodality supportive care ('ThriverCare') intervention on the prevalence of unmet supportive care needs for men and their partner/caregivers. 38 participants with radiologically proven metastatic prostate cancer disease and 10 partners/caregivers were recruited into the study. The study compared the usual standard of care (SC) approach to SC plus ThriverCare intervention. The study concluded that ThriverCare appears to improve the supportive care experience of men with metastatic prostate cancer on hormonal treatment and their partner/caregivers. The results also indicated that care must be responsive and adaptable to meet the individual needs of people affected by cancer to thrive. The new study will build on this results of this study and carry out more intensive research, this time using Australian patients.

May executive committee meeting

At its meeting on Wednesday, 1 May, the executive committee, among other things:

- discussed arrangements for coming meetings and future outreach activities;
- noted that a small working group had developed proposals for the content of the Group's website, which is being redeveloped, and discussed the next steps in this redevelopment; and
- noted reports from the Secretary and the Treasurer.

The next committee meeting will be held on Wednesday 12 June. Group members are welcome to attend meetings of the committee.

Combined Prostate Cancer Support Groups of NSW Conference, Dubbo, 4 to 5 May 2019

President, John McWilliam and Secretary, David Hennessy both attended the Combined Prostate Cancer Support Groups' Conference in Dubbo on 4 and 5 May. This was a great opportunity to get up-to-date information on prostate cancer and its treatment and to meet other support group members and staff of the Prostate Cancer Foundation of Australia (PCFA).



L to R: David Hennessy, John McWilliam, Tom Carroll (Southern Highlands Support Group) and John Leeks (Newcastle Support Group)

The conference included sessions from two urologists (one of whom focused primarily on prostate cancer treatments and the other on bladder and sexual rehabilitation), a radiation oncologist, a medical oncologist and a pathologist. There were also sessions on mental health, the Continence Foundation's Men's Health Campaign, support group issues and (as a bonus) bowel and skin cancer.

On the Saturday evening, the new PCFA Chief Executive, Prof Jeff Dunn AO and his wife, Prof Suzanne Chambers AO both addressed the conference dinner. It was

good to hear about Prof Dunn's plans for the PCFA and his understanding that the PCFA will only be successful if support groups are successful. Prof Chambers is also actively involved in prostate cancer research.



Prof Jeff Dunn speaking at the conference dinner

Many thanks to Elizabeth Allen and her team for making the conference a success.



Elizabeth Allen



Stay up-to-date by joining the PCFA Online Community

The PCFA Online Community is open to everyone who has been impacted by prostate cancer to share their experiences and connect with others. Through the Research Blog, PCFA Online Community members can also learn more about the latest prostate cancer research developments and findings.

The May 2018 edition of the *PCFA Online Community Digest* has articles on:

- prostate cancer related matters covered at the 2019 European Association of Urology Congress [[read article](#)];
- the results of a study assessing the success rate of a new surgical technique to restore sexual function after prostate surgery [[read article](#)];
- lessons from men who haven't been diagnosed with prostate cancer. Men living in outside metropolitan areas in Australia have a higher risk of dying from prostate cancer. There is some evidence that these men are being diagnosed at a later stage, with more advanced prostate cancer [[read article](#)]; and
- combining radium-223 (Xofigo) with Abiraterone (Zytiga) is not recommended [[read article](#)].

It is free and easy to become a member of the PCFA Online Community. You can sign up at:

<http://onlinecommunity.pcfa.org.au>.

Staffing changes at PCFA

As mentioned in the last newsletter, Prof Jeff Dunn AO has recently been appointed as PCFA Chief Executive, and it was good to meet him at the Combined Prostate Cancer Support Groups of NSW conference. Prof Dunn's extensive experience in cancer support, particularly with the Cancer Council Queensland, means that he is ideally placed to ensure that the PCFA actively increases community awareness of prostate cancer, supports prostate cancer support groups and sponsors relevant research into prostate cancer.

After seven years working at PCFA as Director of Support and Community Outreach, Dr Amanda Pomery, has now moved on to take up other opportunities outside PCFA. We thank her for the work she did and wish her well in her new endeavours.

The new Director of Support and Community Outreach is Nikola Ellis. We met Nikola at the Conference of the Combined Prostate Cancer Support Groups of Rural NSW on the weekend of 4 and 5 May. Together with Debra Garroun from Network Support, Nikola said that PCFA will be seeking to provide support groups with responsive support.

PCFA shirts

Would you like to purchase a PCFA shirt? These shirts are available in royal blue in both men's and women's sizing and help to establish visual recognition within the community.



The shirts cost \$23.95 each. Orders need to be placed by **Friday 17 May** (see [order form](#) to make your purchase).

Joining the Group's executive committee

We would like to encourage members with an interest in helping others with their prostate cancer journey to consider joining the executive committee. A number of our committee members have now served for some years and we want to ensure that there is good succession planning. It would help if members who are able to do so could join the committee with a view to gaining a better understanding of the role of the committee, and eventually taking on a committee role or helping to spread the workload of existing members.

Please email John McWilliam or David Hennessy (details above under 'Personal Support') if you are willing to join the committee.

Borrowing items from the library

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 or finding out more about our collection can contact U.N. Bhati, email:

librarian@prostate-cancer-support-act.net

Articles and reports of interest

The following articles which have appeared recently on web sites or other sources may be of interest to some members. Any opinions or conclusions expressed are those of the authors. See Disclaimer below. With thanks to Don Bradfield and Mike Boesen for assistance with this segment.

Testosterone therapy safe despite prostate cancer

Studies presented at the 2019 American Urological Association annual meeting add to a growing body of evidence showing that testosterone replacement therapy is safe for selected men with a history of prostate cancer. The studies found no increase in the risk of adverse oncologic outcomes following treatment—even among men with high-risk prostate cancer—or while on active surveillance. [Read article.](#)

PREDICT Prostate

A Web-based prostate tool, PREDICT Prostate, aims to provide a personalised cancer prognosis. Predict Prostate is a tool where the outcomes from conservative management (or monitoring) are compared with radical treatment (surgery or radiotherapy). The Predict Prostate tool shows you how different initial management strategies affect the percentage of men that survive ten and fifteen years after diagnosis. Non-individualised data is also shown on the potential harms of each treatment type.

The web-based tool was developed based on long-term survival data from a large UK dataset of over 10,000 men who had been diagnosed with non-metastatic prostate cancer. An additional dataset from over 2,500 prostate cancer patients from Singapore was used for external validation. According to study findings, the tool is able to estimate patients' survival anywhere between 10 and 15 years, with up to 84% accuracy. [[Read more](#)]

Understanding hormone therapy with radiotherapy after prostatectomy — how long should the hormone therapy go for?

The following YouTube video gives a good explanation of the results one research study into this issue: [View here.](#)

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, we would 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 to our distribution list, or if you no longer wish to receive copies of the newsletter, please send an email to:

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

John McWilliam

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 does 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 Group. Any recommendations made in such materials may not be applicable in your 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 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.