



THE WALNUT

JUNE 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

Website: <http://prostate-cancer-support-act.net>



Next monthly meeting

Our next monthly meeting will be held on **Wednesday 19 June 2019**.

Our speaker will be urologist, Dr Hodo Haxhimolla, who will update us on current developments in the treatment of prostate cancer and related prostate health issues.

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

Men's Health Week was from 10 to 16 June and it is a reminder that it is important to discuss key issues in men's health and raise awareness of prostate cancer with your family, friends and work colleagues.

It is with great sadness that we learnt of the death of past president of the Group, Peter Daley. Peter was a great supporter of the Group and had a profound beneficial effect on the treatment journeys of many men, including myself. Peter will be greatly missed.

I would like to thank David Hennessy for stepping in for me at our May meeting. I am told that the discussion that was arranged on prostate cancer treatment issues was well received.

We have an interesting program of events arranged for coming months. These are shown on page 4.

I look forward to seeing you at our June meeting, when Dr Hodo Haxhimolla will be speaking to us.

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, 11 June at the Canberra Southern Cross Club, Woden.

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.



Vale Peter Daley

1936 to 2019

Peter Daley will be remembered in Canberra and the surrounding region for the time and effort that he devoted to the welfare of many people and his concern for them.

Peter was an active member and office bearer in a number of friendly associations, and in particular the Prostate Cancer Support Group, ACT Region. Peter was President of the Group from 2008 to 2013.

Under Peter's leadership, the Group contributed greatly to the welfare of prostate cancer sufferers and their partners or carers. His outstanding planning and management skills were reflected in the many educational and support activities undertaken by the Group and for the development of such things as the Group's website and information leaflets on the work of the Group.

As President of the Group, Peter chaired a large number of regular monthly meetings, which were attended by a host of people who sought information, advice, counsel and support relating to prostate cancer.

Peter arranged for many health professionals and specialists to give informative presentations at those meetings. His chairing skills were remarkable and led to extremely useful exchanges of information between presenters and members.

Peter organised and undertook many presentations for work groups and clubs, some as far afield as Cooma and Harden-Murrumburrah. He was an excellent presenter and represented the Group at events organised by the Prostate Cancer Foundation of Australia. He was a great ambassador both for the Group and the PCFA.

Peter organised the Group's participation in major community events, such as the Murrumbateman Field Days, Canberra Multicultural Festivals, Seniors Expositions, Men's Sheds, Autofests, Show 'n Shine bike events, Canberra Shows, PM's Cricket matches and many others, where information was made available about prostate health, the Group's aims and activities.

Peter took an active involvement in the management of the Group's finances. He was instrumental in the Group's provision of funding for worthy causes, such as support to nurses undertaking specialist training courses for the care of prostate cancer patients and testing equipment for the Canberra Hospital.

Peter will be remembered for his unflappable demeanour, unlimited energy and willingness to spend a vast amount of time in undertaking work on behalf of the Group, prostate cancer sufferers, their partners and carers in the Canberra region and elsewhere. Members will also remember the contribution that his wife, Patricia, made in supporting Peter. She gave a great deal of her time attending events and meetings with Peter and working at the Group's marquees.

The Group expresses heartfelt condolences to Patricia, who has lost a great companion and one who contributed a great deal to the welfare of the community.

Our May meeting

Secretary, David Hennessy outlined the form of the meeting for the night, which was to report on the NSW Rural Conference of Support Groups, to outline notices of coming events and then prepare members for small group discussions of possible treatment for hypothetical cases of prostate cancer.

A draft copy of the report on the NSW Rural Conference of Support Groups was provided for members to peruse and discuss.

There was an information notice from the Mental Health Foundation ACT about their workshop on 28 May (Composting and Worm Farming) at the Canberra Environment Centre and a petition circulated calling for the retention of the hydrotherapy pool at the Canberra Hospital. A number of members signed the petition which, after the meeting, was forwarded to SHOUT.

Members separated into four groups of four to discuss the following:

What might be the approach of action for a man with the following Gleason scores?

a) 3+3, b) 3+4, c) 4+3 or d) 4+4,

and men of the ages of either a) 60 b) 65 or c) 70 years at diagnosis?

Given the option of a) active surveillance b) ADT (e.g Zoledec) b) radiotherapy c) radical prostatectomy or d) chemotherapy or combinations of some?

June executive committee meeting

At its meeting on Wednesday, 12 June, the executive committee, among other things:

- received a progress report on the redevelopment of the Group's website;
- discussed possible speakers for meetings in late 2019 and early 2020;
- noted that the Group would be undertaking an outreach activity at Isabella Gardens on Sunday, 21 July;
- agreed to invite SHOUT to assist with contacts with urologists and radiation and medical oncologists to display information about the Group for prostate cancer patients in their surgeries;
- received reports from the Secretary and the Treasurer;
- agreed to make a donation of \$2,000 to the Prostate Foundation of Australia's research program;
- noted arrangements for the audit of the Group's financial statements; and
- discussed ways in which the Group could maintain contact with, and help support, members who now have limited involvement in the Group's meetings or who may be unwell.

The next committee meeting will be held on Wednesday 3 July. Group members are welcome to attend meetings of the committee.

Future meetings

17 July 2019	Visit to the new Icon Cancer Centre in Belconnen, with radiation oncologist, Dr Andrew Lee, and other centre staff in attendance and a tour of the centre.
21 August 2019	Cathie O'Neill, Canberra Region Cancer Centre will speak about the new Wellness Centre
18 Sep 2019	Annual General Meeting. Maureen Bailey, physiotherapist.

NAVIGATE trial

This is a reminder about the NAVIGATE trial that is being run by the Peter MacCallum Cancer Centre in Melbourne. The Peter Mac Cancer Centre is running this trial, in conjunction with Swinburne University of Technology. Men with low risk prostate cancer, and their partners, are needed to take part in the study which is assessing Navigate, a new online tool designed to help men navigate their treatment.

For more information on the trial, please contact Project Manager Natalie Richards on 03 8559 7453 or email navigate@petermac.org.

Max Gardner Award for Distinguished Service

The Max Gardner Award for Distinguished Service is a prestigious award presented by PCFA. It is awarded to an individual member of the Network who has made an outstanding and significant contribution to reducing the impact of prostate cancer on Australian men, their partners and families, recognising the diversity of the Australian community. This award is a peer-based form of recognition for PCFA Network members who are currently an official Ambassador, in a Support Group Leader role or an active member of an affiliated support group.

The Max Garner Award recipients for 2018 have now been announced. They are:

- David Merry;
- Mary Jones; and
- Tony Maxwell.

Read more about the recipients [HERE](#).



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

The PCFA Online Community is open to anyone 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 June 2019 edition of the *PCFA Online Community Digest* has articles on:

- prostate cancer with low PSA. A high reading on a PSA blood test can pick up prostate cancer early. But not all prostate cancers have a high PSA. Some men are diagnosed with an aggressive prostate cancer but still have a very low PSA level. [Read more](#).
- antibodies for treating prostate cancer. Researchers have successfully made an antibody to target prostate cancer. This antibody binds a protein called PSMA, found on the surface of prostate cancer cells. It is a 'biological tool', with the potential to be part of a new therapy targeting prostate cancer. [Read more](#).
- PSA testing for men who have had treatment for an enlarged prostate. Focal therapies are experimental treatments for

localised prostate cancer. Focal therapies destroy small tumours, preserving some of the prostate gland. The aim is to treat the cancer with less side effects than surgery or radiotherapy. But what happens if prostate cancer comes back after focal therapy?

[Read more](#).

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

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

PCFA fundraising



As part of its fundraising efforts, the PCFA is again promoting the Entertainment™ Book.

The Entertainment™ Book is a local restaurant and activity guide which provides hundreds of offers including: up to 50% off and 2-for-1 offers for the finest restaurants, cafes, attractions, activities, retailers and hotels around Australia. The book comes with a Gold Card and vouchers valued at over \$20,000. The Membership entitles buyers to exclusive offers that are virtually restriction-free, the membership is available to use now and expires 1st June 2020.

Alternatively, there is also the option of a digital membership. The Entertainment™ Digital Membership puts the value of the traditional Entertainment™ Book into your Apple or Android device, and also allows you to:

- show and save using your Apple or Android device, with no card or voucher to present;
- search for nearby businesses in the Entertainment™ program;
- search for specific businesses by name, location or dining category; and
- share your Membership with another family member.

If you, your friends or family are interested in this year's Entertainment™ Book (hard cover or digital) please consider ordering through this [link](#) and 20% of your membership will contribute towards PCFA fundraising efforts.

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

The library has recently acquired *The Keep it Healthy Prostate Playbook*, by Craig Allingham. Craig Allingham is a leading Australian physiotherapist, with expertise in sports science and medicine and men's health. *The Prostate Playbook* is for men choosing to avoid treatment side effects by taking an active role in suppressing, sabotaging and undermining their cancer and those looking to reduce the risk of recurrence following treatment.

The Group also has a copy of Craig's first book, *Prostate Recovery MAP — Men's Action Plan*, which provides a program to assist recovery of continence and erectile function for men who have undergone treatment.

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.

Free online course on radiation oncology for cancer patients, their families and other health professionals

The following course about radiation treatment for cancer, run by Trinity College Dublin, is designed for non radiation oncology professionals and will be of interest to many members: [An Introduction to Radiation Oncology: From Diagnosis to Survivorship](#).

Prostate Cancer Patient Guide

The US Prostate Cancer Foundation has published an updated Patient Guide. The Foundation states that the Guide is for any man who has been newly diagnosed, who is in treatment, or is concerned about a rising PSA. Beyond that, it's for any loved one or caregiver who wants to cut through the information noise and get directly to need-to-know information for prostate cancer patient navigation. Lastly, as we are beginning to recognise the genetic underpinnings of cancer, this guide is for any family member who might want to understand how their shared genes affect their own short- and long-term risks factors—and whether they should be screened as well.

[Download a copy of the Guide.](#)

Prostate cancer therapy weakens muscle strength

Androgen deprivation treatment (ADT) for prostate cancer is leaving men with less muscle strength and relatively low muscle mass compared with healthy men, researchers from Deakin University say.

The study examined the muscle and fat in 70 men treated with ADT for prostate cancer compared with 52 men with prostate cancer not treated with hormone therapy, and 70 healthy men of a similar age.

The results showed that when measures of muscle strength were expressed relative to weight, men treated with ADT had lower hand grip (15-17%), chest (15%), and back (15-16%) muscle strength compared with both controls.

Furthermore, those on treatment had 15% lower leg muscle strength per kilogram of body weight compared with healthy controls.

The researchers suggested that adiposity-based adjustments be considered when assessing muscle-related outcomes in men treated with ADT.

[Read article.](#)

Study supports stereotactic body radiotherapy as a standard of care for localised prostate cancer

External beam radiotherapy, a method that involves delivering radiation beams to a patient's tumour, is an effective treatment for men with localised prostate cancer.

Traditionally, this type of radiotherapy was delivered in small daily doses over eight to nine weeks to spare the healthy tissues adjacent to the tumour. However, a serious drawback to this approach is the number of

times the person has to undergo radiotherapy.

Stereotactic body radiotherapy (SBRT) allows treatment in just four to seven sessions. SBRT works by giving radiotherapy from many different angles around the body. The beams meet at the tumour, hitting it with a high dose of radiation, while the tissues around it receive a much lower dose. This technique has been optimised in recent decades.

A recent review of 38 published prospective studies supports SBRT— a highly precise radiation therapy delivered in shorter periods of time — as standard of care for localised prostate cancer. The study found that:

- after five years, 95.3% of patients remained without any signs of cancer recurrence, and 93.7% reached the seven-year mark free of cancer recurrence;
- few patients experienced acute severe side effects (fewer than 1%) or long-term severe side effects (2% for genitourinary and 1.1% for gastrointestinal toxicity rates); and
- while treatment worsened the patients' bowel and urinary functions, these returned to baseline levels within a 2-year period, but sexual function continued to worsen with time.

[Read article.](#)

Hormone therapy after radiation — when to use

Useful [You tube video.](#)

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.