



THE WALNUT

JUNE 2021

Newsletter of the Prostate Cancer Support Group—ACT Region

Affiliated with the Prostate Cancer Foundation of Australia (PCFA)

Postal address: SHOUT, Building 1, Collett Pl, Pearce ACT 2607

<https://prostate-cancer-support-act.net>



Monthly meetings

Our regular meetings are held on the third Wednesday of the month (except in December) in Room 22, Building 1, Pearce Community Centre, Collett Place, Pearce, ACT 2607 ([see map](#)).

Our next monthly meeting will be held at **7:00 pm on Wednesday, 14 July**, but will be a bit different - we're going to run this one as a social function at [The Statesman Hotel](#) in Curtin, and we'll be sending out more details closer to the date. This should be fun!

Next coffee morning

Our coffee mornings are normally 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 next coffee morning will be held at **10:00 am, Tuesday, the 13th of July** at the **Woden Southern Cross Club**.

All are welcome to attend our meetings and coffee mornings, and we'd love to see you there.

PCFA turns 25 this year!

PCFA will be holding its 25th Anniversary Support Network Conference in Dubbo between 22-24 October and you're invited to attend!

The conference will bring together around 150 experts and Support Network Members from around Australia to share knowledge and build capacity in prostate cancer control. Importantly, it will mark the next step in PCFA's translational research program to establish a National Prostate Cancer Survivorship Essentials Framework, leveraging from the data recently released in association with the STARGATE Project, to improve prostate cancer awareness and save lives. Exciting times, indeed!

The program will include:

- registration, a walkthrough of Dubbo's RFDS Visitor Centre and welcome reception on Friday, the 22nd;
- informative and engaging conference sessions on the 23rd and 24th; and
- the 25th Anniversary Dinner on the night of the 23rd, where the keynote speaker will be Steve Grahame, star of the ABC series 'Outback Truckers'.

Best known for his starring role in the documentary series Outback Truckers, few Australians know that WA trucking legend Steve Grahame is also a prostate cancer survivor. Renowned for lending a helping hand wherever the road takes him, he will be pulling up in Dubbo to speak candidly about his own diagnosis.

A full description of the Conference is shown [here](#).

If you'd like to attend, please register before the 27th of September with Elizabeth Allen [here](#). To help, she has also compiled a list of motels for you to book [here](#).

We hope you can come!

Exercise and Prostate Cancer - How Can It Help Me?

Well, numerous studies have shown that exercise plays an important role in our treatment and recovery from prostate cancer through reducing the number and severity of treatment-related side effects and symptoms (including fatigue, muscle loss, anxiety and depression), as well as improving or maintaining function during and after treatment. There is also evidence that men who are physically active after a prostate cancer diagnosis have reduced risk of recurrence, reduced risk of developing other chronic diseases, and have better overall survival.

The ABC's Catalyst TV program looked at how targeted exercise can help fight cancer in 2016 - you can download it [here](#).

To coincide with Men's Health Week, Dr Kellie Toohey from the University of Canberra (UC) spoke at our June meeting, where she discussed the:

- role of exercise in dealing with prostate cancer; and.
- Prehabilitation, Activity, Cancer, Exercise and Survivorship (PACES) research group, which is investigating the effect of exercise on cancer patients and those living post- cancer.

PACES is using a multi-disciplinary approach to research improvement for cancer patients and their loved ones, and includes researchers from UC and nationally, medical oncologists, specialist nurses, exercise physiologists, nutritionists and dietetics, clinical psychologists, physiotherapists and consumers.

What can exercise do for me?

- Maintain bone health and muscle strength
- Improve mental health, mood and sleep quality
- Improve fatigue management, quality of life, sexual health and incontinence
- Improve immune functions, balance and coordination
- Reduce risk of other diseases, including cancer returning
- Improve treatment completion rates improve, and help patients tolerate treatments better
- Reduce Chemotherapy Induced Peripheral Neuropathy (CIPN), such as numbness and pins and needles

So what should we do?

- Decrease our sedentary behaviour - get up and move!
- Slowly increase activity levels to 30 mins/day of moderate aerobic exercise (to a minimum of 150 mins/week) – this is when you start to huff and puff, but can still hold a conversation.
- Implement resistance-based exercise (two times a week) using weights.
- Improve healthy eating and lifestyle choices.
- Get the right advice to help it in with your lifestyle, go get support when you need it, and don't put up with changes that can be helped with exercise.

More about how exercise can help survivors of prostate cancer and how you can access exercise physiology support can be found [here](#) and [here](#). Good luck and get out there!

Current Activities

We're helping to launch MatesCONNECT! As discussed on page 1, we're going to run our monthly meeting as a social function at The Statesman Hotel in Curtin, where we'll be joined by PCFA as they launch the MatesCONNECT telephone-based peer support service here in the ACT. This will be a significant event for us so please come and join us.

ACT Hockey Donation. On the 10th of June, we were advised by Leo Clarke, President of ACT Masters Hockey, that they wanted to make a donation to us as a result of their recent fundraising evening. Greg McRoberts, our President, has accepted their kind donation on our behalf and we'll be maintaining contact to see if we can assist with their next fundraising activity in April 22 by supplying some members to assist with raffle ticket sales. Thank you, ACT Masters Hockey!



Men's Health Week. On Wednesday, the 16th of June, Georgia Stynes spoke with our Secretary, David Newman, on ABC Radio Canberra's Afternoons Show as part of Men's Health Week. You can listen to the interview [here](#).



Membership database update. It's done! Phew! Our membership database now records three major categories of members and our supporters:

- **Full members**, who will retain full voting rights and receive emails about our upcoming meetings and the minutes from past meetings;
- **Inactive members**, who have asked to reduce the level of their engagement in our group and not receive emails about our upcoming meetings or minutes from past meetings; and
- **Support network**, who provide ongoing support to us, and include urologists, nurses, government officials and representatives of PCFA and Cancer Council.

We have ended up with about 170 of you as our Full members, so that will make it easier to run our Annual General Meetings (AGMs). However, we haven't been able to re-establish contact with nearly 60 people who were on our records, so we'll be tabling them at the Annual General Meeting for your consideration. **If you think that you might have been put in the wrong group (eg. you want to attend our meetings but aren't hearing about them), please email Dave Newman at secretary@prostate-cancer-support-act.net** so that we can update your records.

Committee membership. Having a strong and engaged committee is fundamental to keeping our Group going and staying strong. We currently have a couple of committee members who will be retiring at our next Annual General Meeting, which is planned for the second Wednesday in September this year, so we're starting to look for their replacements early.

The Committee has three legislated positions (ie. the President, Secretary and Treasurer) and two ex-officio positions, so the work can easily be spread across the team and is not onerous. If you'd like a chance to join the Committee and help with the future direction of your Group, please [email the Secretary](#) and advise if there is a particular role that you'd like to help with. We'd love to have you on the team!

Articles and Reports of Interest

The following articles may be of interest to members. Any opinions or conclusions expressed are those of the authors. Please see the Disclaimer at the end of this edition of the Walnut.

Patterns of care for men with prostate cancer: the 45 and Up Study

The objectives of this study were to describe patterns of care in New South Wales for men with prostate cancer, and to ascertain factors associated with receiving different types of treatment.

The study reviewed 4003 men aged 45 years or more from NSW in whom prostate cancer was first diagnosed during 2006–2013.

The study found that men with prostate cancer were **twice as likely to have radical prostatectomy as to receive EBRT**, and fewer than one in seven had consulted radiation oncologists prior to prostatectomy. The treatment received was influenced by several socio-demographic factors. Given the treatment-specific side effects and costs, policies that affect access to different treatments for prostate cancer should be reviewed. [Read more here](#)

Earlier Screening Urged for Relatives of Prostate Cancer Patients

According to a study published 1 Jun 21 in PLOS Medicine, the optimal age for starting prostate cancer (PCa) screening in relatives of patients with PCa is younger than that in the general population, and varies by the number of first-degree relatives with PCa as well as their age at diagnosis.

The study found that men with family history of prostate cancer reach the screening risk threshold up to 12 years earlier than men in the general population.

- For men with **two or more first-degree relatives diagnosed with PCa and the youngest relative diagnosed before age 60 years**, this screening level was reached at age 41 years.
- With **two or more first-degree relatives diagnosed after age 59 years**, men reached this screening level at age 43 years, which was similar to that of men with one first-degree relative diagnosed before age 60 years.
- The screening level was reached at age:
 - **45 years** when one first-degree relative was diagnosed **between ages 60 and 69 years**, and
 - **47 years** when one first-degree relative was diagnosed **after 69 years**.

[Read more here](#)

Advances in prostate cancer diagnosis and management

Management of prostate cancer has changed significantly in recent years with the introduction of prostate MRI as routine in the diagnostic pathway, and increasing use of prostate-specific membrane antigen positron emission tomography for early stratification in the salvage setting for failure of primary treatment in localised disease.

Upfront combinations of ADT with other systemic treatments have yielded significant gains in overall survival for patients with metastatic disease. Association between germline DNA repair defects and progressive disease, and interest in the potential to identify patients for therapies that target these defects have also been recognised.

[Read more here](#)



PCFA Online Community

PCFA runs Australia's largest online group dedicated to connecting Australian men and families who have been impacted by prostate cancer. By joining the conversation in their Community Forum, you can learn more about medical and other scientific breakthroughs. You can access the Community [here](#).

MatesCONNECT

MatesCONNECT is a telephone-based peer support service for men affected by prostate cancer, and can connect you to a trained volunteer who understands what you're going through. All MatesCONNECT volunteers have been through prostate cancer.

You can get practical advice on surgery and treatment, and the side effects of treatment, such as incontinence, erectile dysfunction, and coping with hormone therapy.

Simply call PCFA on [1800 22 00 99](tel:1800220099) to be connected with a volunteer.

Partners and Prostate Cancer: You're Not Alone

PCFA has just posted a new page on their website that will be of interest to our carers.

When you hear your loved one has prostate cancer, you may find yourself dealing with feelings of fear, anxiety, anger, depression and loss. Many feel they are on an emotional roller coaster. On a practical level, your life may change overnight so if this is what you're feeling, PCFA has good advice for you [here](#).

[Download your Mar 21 Blue Sky News here](#)



Cancer Council 13 11 20

Cancer Council 13 11 20 is a free, confidential telephone information and support service.

Their specially trained staff can answer your questions about all aspects of cancer, including prevention, early detection and treatment. They can also assist with practical and emotional support as well as referring you to appropriate services in the area.

They are open Monday to Friday, from 9am – 5pm. Outside these hours, you can leave a message and they will call you back.

Legal and Financial Matters

Cancer Council ACT runs free seminars for people affected by cancer that will cover a range of financial and legal matters you may face. These include early access to superannuation; Centrelink benefits and eligibility; wills, powers of attorney and guardianship; and other issues commonly faced by cancer patients and their families.

For information, please call [02 6257 9999](tel:0262579999) or email reception@actcancer.org.

Publication: Fatigue and Cancer

This fact sheet has been prepared to help you understand and manage fatigue, a common side effect of cancer and cancer treatments.

Fatigue is when you feel very tired, weak, drained and worn out. Cancer-related fatigue is different to normal tiredness because it doesn't always go away with rest or sleep. Even though fatigue is common, managing it is an important part of cancer care.

[Download the publication here](#)

Appreciation

Thank you to PCFA, the ACT Government, SHOUT, ACT Masters Hockey, Paddywack Promotional Products, Harness Racing ACT, and everyone supporting our fund-raising and other activities.

Social Media

Facebook has a range of Open and Private groups that may be of interest to you:

- [Prostate Cancer Foundation of Australia](#) (Open)
- [Prostate Cancer Foundation of Australia Support Groups](#) (Private)
- [Prostate Cancer Support Australia](#) (Private)

Borrowing items from the Library

You can borrow items from the Group's library, which has a wide range of books and videos. Those who are interested in borrowing items or have suggestions for additions to our library can contact U.N. Bhati by email: librarian@prostate-cancer-support-act.net

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:

President: Greg McRoberts

Phone: 0413 480 864

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

Secretary: David Newman

Phone: 0412 812 875

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

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

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.