



THE WALNUT

JULY 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, 18 August**, where we will be joined by one of our members, Dr Michael Fullam-Stone, who will be talking about helping us to better understand treatment options, and introducing concepts for stress dissipation, healing, etc. using mind power. Our COVID Safety Plan remains in place so please check in on the app when you arrive.

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 10th of August** at the **Jamison Southern Cross Club**.

MatesCONNECT is live in the ACT!

PCFA's MatesCONNECT service was soft-launched here in the ACT on the 15th of July and will help connect newly diagnosed men with trained volunteers who have been through the disease.

MatesCONNECT has been supported by the ACT Government under the ACT Health Promotion Grants Program in order to help provide more local support services, noting that:

- more than 3,300 men in the ACT are living with prostate cancer and an average of 260 new cases are diagnosed each year,
- about one in five men with prostate cancer will experience long-term anxiety and depression, and
- men with prostate cancer face a 70 per cent increased risk of suicide compared to the general population.

The launch was picked up by media throughout the ACT and region, with an article in the Canberra Times, a live interview on 2CC and footage on WIN News, so the word certainly got out.



We supported PCFA with our own little soft-launch the night before at our social function at The Statesman Hotel. We were hoping to be joined by our friends from PCFA but COVID border closures soon put a stop to that!

If you'd like to help and be a MatesCONNECT volunteer, check out how to on [page 5!](#)



Mental Health - RU OK?

'A conversation could change a life'

Our Mission includes providing ongoing peer support to men and those in their lives who have experienced the life changing effects of a prostate cancer diagnosis. Although we often focus on the physical aspects of prostate cancer, our mental health can be adversely affected, too.

For many of us, a cancer diagnosis can have a profound emotional effect and may be one of the most stressful life events you ever experience. Your initial diagnosis can come as a real shock because prostate cancer isn't always accompanied by symptoms or indications that something is wrong. Common reactions that we can experience include shock, fear, anger, anxiety and confusion. Importantly, there is no right or wrong way to react or feel – each of us will have our own individual way of reacting and coping. And afterwards? Do our fears ever really go away?

Research shows that 1 in 5 men with prostate cancer experience long-term anxiety and depression, but sadly, 72 per cent of those men impacted by prostate-related mental health issues will not seek help. That's nearly three quarters of us who need a hand.

In April this year, Prof Jeff Dunn AO, PCFA CEO, spoke about this, highlighting the following:

"Alarmingly, Australian men with prostate cancer have a 70 per cent increased risk of suicide, compared to the general population."

"By working together, we can stop men from suffering in silence. In addition to providing better support services, we need all Aussies to commit to checking in on the men in their lives to ask how they are and be there when times are tough."

"This can be as simple as putting in a call to someone you know who has been impacted by cancer, sending someone a message or taking them out for a coffee."

PCFA has a range of helpful information guides that can help with your mental health for both the newly diagnosed and those of us who continue to live with the disease and its aftermath:

- ['Maintaining Wellbeing with Prostate Cancer'](#) (ISBN 978-0-9941841-6-0)
- ['Understanding Health and Wellbeing with Prostate Cancer'](#) (PCFA13465_Dec_2020)

We can also reach out for support through PCFA's MatesCONNECT or telenursing services to speak with a trained cancer specialist nurse; both services can be reached on [1800 22 00 99](tel:1800220099).

But, in addition to this, what can WE do for EACH OTHER, here and now? Well, **we can talk and be there for each other**. As the RU OK program has shown, this can be as simple as asking, listening, encouraging action and then checking back in if we think one of our mates is having a rough trot. Just remember - every day can be the right time to ask 'RU OK?'



The key here is that we need to talk, be willing to seek help and be willing to listen when others seek our help. Like any life-changing event, the mental health impacts of prostate cancer diagnoses and treatments can be significant and enduring - they can't be surgically excised. **It's ok to feel down - that's what makes us human. But it's also right to speak up and seek help.**

Current Activities

July's Social Function - that was fun! As discussed in the last Walnut, we decided to run our July monthly meeting as a social get-together for a change, so we headed over to The Statesman Hotel in Curtin and had a great night out! It was a lot of fun to just catch-up and chat with everyone over a nice pub dinner so hopefully we can run a few more like this. How often and where do you think we should run them? We'd love to know what you'd like to see so please [email the President](#) and give him your ideas of where and when!



Annual General Meeting. Our Annual General Meeting is planned for Wednesday, the 8th of September, and we'll be sending out the agenda and supporting notes to Full members soon. This year, we'll be able to have people join by Skype and you'll also be able to vote by proxy if you can't join in the meeting itself.

As you would know from previous Walnuts, we currently have a couple of committee members who will be retiring at our next Annual General Meeting and will need to be replaced. The Committee has three legislated positions (ie. the President, Secretary and Treasurer) and two ex-officio positions. 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 and help support our Group!

Internet update strategy. As discussed in our May Walnut, we're currently updating our internet presence, thanks to a lot of hard work by Mark Jardine and Greg McRoberts, so you'll shortly hear of our new web address and email addresses. Standby! It'll be great.

PCFA's Support Network Conference Dubbo - 22-24 October. As discussed in the last Walnut, 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.

The conference program will include:

- registration, a visit to Dubbo's RFDS Visitor Centre and a welcome reception on the 22nd;
- interesting 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'.

The Conference program is shown [here](#). If you'd like to attend, please register before the 27th of September with Elizabeth Allen [here](#). Elizabeth has compiled a list of nice motels for you [here](#).

Articles and Reports of Interest

The following article 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.

PSA testing 'overused' in older asymptomatic men

A recent general practice study published in 'Australian Doctor' has reviewed primary care data and concluded that PSA testing is still being overused in asymptomatic men aged 70 and older, potentially causing more harm than good. The findings, based on data from 142,000 primary care patients, suggest the 2016 updates to prostate cancer screening guidelines have failed to curb the use of the test in the elderly. The study drew in data for all male patients who attended the same practice in Victoria between 2016 and 2018.

An offer of biennial PSA testing is recommended for men aged 50-69, provided they are informed of the harms and benefits of the screening tool. However, the guidelines suggest that over-70s should be advised "the harms of PSA testing may be greater than the benefits of testing in men of their age".

Overall, PSA testing prevalence, proportion of those tested more than once in a 24-month period, and median PSA levels each increased with age, the study authors said.

"For men over 69 years of age, this could lead to further invasive tests and treatments, some of which may be unnecessary or cause harm," the study authors wrote.

The high testing prevalence in older men "was similar to previous Australian reports (48% of men aged 70 years or more reported they had PSA tests in the preceding two years), and the PSA levels matched current age-specific 95th percentile reference ranges. Why patterns of testing are different to those recommended ... cannot be explained by general practice data, but reasons may include patient expectations, fragmentation

of care and the persistence of old guideline recommendations," the researchers said.

However, despite their calls for improved decision-making and better adherence to the 2016 guidelines, a leading urologist has suggested an overhaul of the guidelines was warranted to take account of advances in technology and changes in clinical practice over the past five years.

Professor Mark Frydenberg, former president of the Urological Society of Australia and New Zealand and co-author of the guidelines, said the document was "outdated and in urgent need of review".

"There's been a whole paradigm shift since 2016, which heavily tips the balance of potential benefits and harms in favour of PSA testing," Professor Frydenberg told MJA Insight.

The availability of Medicare-funded multiparametric MRI scans, as well as biopsy techniques reducing infection and improvements to treatment, had drastically reduced the harms associated with screening.

"Prior to 2016, virtually everyone diagnosed with prostate cancer ended up having radiotherapy or surgery," he said.

"Now a large number of men are deemed to have low-risk prostate cancer and don't need surgery or treatment at all and are managed closely with surveillance."

More articles next month!



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. You can get practical advice on surgery and treatment, and the potential 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.

And if you'd like to become a volunteer yourself, [read this](#) and then [email PCFA here](#).

Know Your Family History

Most of us understand that your risk of being diagnosed with prostate cancer is affected by your family history but it's not as simple as the oft-quoted 'twice the average risk'. Did you realise that if you have two or more close male relatives who have been diagnosed, your lifetime risk increases **five-fold**? Your risk also increases if you have a strong family history of breast or ovarian cancer. PCFA has some great advice [here](#), so please read it and if you have sons and brothers, talk to them!

[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.

Cancer and COVID-19

If you have cancer, your immune system may not be as strong as it is normally so you may feel concerned about risks associated with COVID-19. Generally, you should continue to follow any specific advice or standard precautions recommended by your health care practitioners to minimise your risk of infection, during and after treatment.

Cancer Council Australia has some great guidance regarding COVID-19 for you [here](#).

Publication: Emotions and Cancer

This booklet has been prepared to help you understand more about the emotional impact of cancer and the range of reactions that people may have. It offers suggestions for adjusting to the diagnosis and coping during and after treatment, as well as information about support services. The booklet also provides practical tips on how to talk to others about cancer and how they can help.

[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.