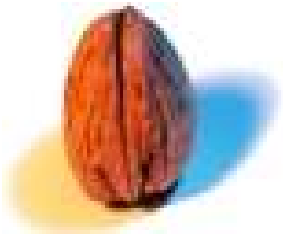

# THE WALNUT

October 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://pcsg-act.org.au

## Our 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 a social event and held at **6:00 for 6:30 pm** on **Wednesday, 17 November,** at **Snapper on the Lake**, which is underneath the Southern Cross Yacht Club, Mariner Pl, Yarralumla. We'll be dining outside on the shores of the lake and it'll be BYO if you'd like a tipple (or two!) as we watch the sun set. If it rains, we'll head upstairs to the dry so come along!

## Our Coffee Mornings

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

- Odd months (eg. January, March, etc) are held at Jamison.
- Even months, (eg. February, April, etc) are held at Woden.

Because we were in lockdown during the second week of October, our next coffee morning will be on **10:00 am, Tuesday, the 9th of November** at the **Jamison Southern Cross Club**.

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

## Annual General Meeting

We held our 2021 Annual General Meeting (AGM) by Skype on Wednesday, the 29th of September, so thank you for everyone who joined us online or voted beforehand by proxy. This was the first time that we've held an AGM itself entirely online and been able to boost this with proxy votes so we've definitely moved into the online age!

The AGM reported to us that over the last year, we've:

- updated our Constitution,
- developed a Strategic Plan to direct our future actions,
- updated our internet presence and done it cheaper, and
- validated our membership and added a few new categories go better reflect how we can support and engage you.

At the AGM, we voted in a new Committee (with a couple of old names), so please welcome Roger Carthey and Andrzej Pietkiewicz to the Committee and thank our retiring members, Peter Baker and John Richmond, for everything they have done for us over the years. Roger and Andrzej have big boots to fill, but are ready and willing to step up to the challenge.

Things are looking good for our Group this year but we're always ready to make things better again for you, so if you have any ideas on where you'd like better support, please drop a line to us here.

## Post-shutdown – Where are we going?

Although the ACT has exited shutdown and we're now adapting to a New Normal, we're continuing to take prudent precautions because the nature of our Group is that a number of us are elderly and at risk because of our ongoing cancer treatments. For this reason, the Committee has decided that until the end of the year, our traditional monthly meetings will be held online, instead of us meeting at SHOUT, and we'll continue to offer online attendance into the future. Although we can't mandate vaccination, we also **strongly encourage** that members only attend future meetings, including our social events, if double-vaccinated.

# Leo's Place – *'A Place to Rest Awhile'*

Ann Monahan joined us at our October monthly meeting to discuss 'Leo's Place', which provides respite care for patients and carers alike.

Respite care is not the same as end-of-life palliative care. Importantly, Leo's Place is not a hospice. Instead, it is a four-bedroom home in Braddon that provides temporary respite accommodation with cooking facilities for up to eight people for:

- **overnight respite** – for people with a life-limiting illness, with the option of their carer staying with them;
- **day respite** – providing support and care for people with a life-limiting illness, to allow carers to have a short break; and
- **carer support** – access to advice, information and self-care activities

**How is Leo's Place different?** Most people with a life-limiting illness want to remain in their own home for as long as possible. In addition, caring for someone with a life-limiting illness can be both rewarding and demanding, for both the carer and their loved one. For many, it is a privilege and strengthens relationships. However, caring for those with a life-limiting illness can also be incredibly challenging at a time when we can all be at our most vulnerable. Many carers willingly put all their time and energy into caring for their loved one but, over time, this can result in fatigue and isolation.

Supporting people to achieve their goal of staying at home for as long as possible requires better support of those with a life-limiting illness and their carers. Recognising this, Palliative Care ACT has worked to offer non-clinical respite for people with a life-limiting illness and their carers. This is where Leo's Place comes in.

**Who can visit and stay at Leo's Place?** Those who visit Leo's Place will be:

- living or caring for someone with a medically diagnosed, life limiting illness,
- able to self-administer their own medications,
- able to attend to most activities of daily living with stand-by assistance provided by support workers, and
- able to access clinical services as if they were at home.

**What sort of Carer Support is offered at Leo's Place?** Carer Support offered at Leo's Place can include:

- counselling and emotional support,
- assistance with navigating support services,
- financial advice and planning, and
- activities to promote wellbeing – e.g. yoga, massage.

**How can I access Leo's Place?** People can self-refer to Leo's Place for up to a week and can stay there with their carers. If you know someone who might benefit from respite and want more information, contact Leo's Place on 6171 2290 or email here.

## Would you like more information?

- You can download a printable brochure here.
- You can also here for a link for virtual tour of Leo's place.

# Current Activities

**COVID Safety Plan.** We've checked the current ACT guidance and our COVID Safety Plan is still valid. That said, please feel free to continue to wear masks at our meetings if you would like and, as discussed earlier, we also **strongly encourage** that you only attend future meetings, including our social events, if double-vaccinated for the safety and confidence of others.

**Social Activities.** We're going to follow-up our successful mid-year social event last July with more catch-ups next year in lieu of our traditional monthly meetings. Our next social event will be this month to wrap up the year and will be held at 6:00 for 6:30 pm on Wednesday, 17 November, at Snapper on the Lake, which is underneath the Southern Cross Yacht Club, Yarralumla.

**Assistance with Continence Aids.** In January this year, we sent out an email advising that one of our members had kindly donated a range of incontinence pads and underpants for any of you that may need them. We still have a number of these in stock so if you'd like any, please email us and we can arrange for you to come and pick them up. Another of our members has also recently provided us with detailed advice about the Federally-funded Continence Aids Payment Scheme, which provides payment to assist eligible people who have permanent and severe incontinence to meet some of the cost of their continence products.

- CAPS clients will receive a payment which is indexed annually. The current payment is $635.10 for the financial year 2021-22.
    - The CAPS payment is income tax exempt and will not be included in any Centerlink assessment as income.
    - Clients can choose one full payment in July, or two half payments in July and January each year.
- Eligibility criteria are listed here and include where '*the applicant has permanent and severe incontinence of bladder and/or bowel function due directly to an eligible neurological condition*' disorders, including the bladder or bowel innervention disorders listed here:
    - Bladder Post Bladder Surgery,
    - Prostatectomy with nerve removal or damage, and
    - Radical Prostatectomy
- The Scheme's guidelines and application form can be found here.
- The Continence Foundation of Australia has a list of products that may help you to choose the best product for you. You can buy continence aids products at supermarkets, pharmacies, online or by phone

# 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.

## Survival Outcomes in Older Men with Non–Metastatic Castration-Resistant Prostate Cancer treated with Androgen Receptor Inhibitors

In this follow-up study of the effects of short-term androgen deprivation therapy (ADT) administered in combination with radiotherapy (RT), the 10- and 18-year overall survival rates were respectively:

- 56% and 23% with RT alone, and
- 63% and 23% with combination therapy.

The estimated restricted mean survival time at 18 years and the 10- and 18-year disease-specific mortality were significantly improved with the combined therapy, with improvements in biochemical failure and distant metastases also observed. No significant differences in adverse events were observed between the treatment groups.

At approximately 15 years of treatment, the addition of ADT to radiotherapy is estimated to improve overall survival by an additional six months.

Read more here

## Real-World Practice Patterns and Predictors of Continuous versus Intermittent ADT Use for Prostate Cancer in Older Men

Intermittent androgen deprivation therapy (IADT) has been shown to be noninferior to continuous ADT, but real-world utilization of this strategy is not well-known. The authors of this retrospective study evaluated 8544 men older than 65 years with prostate cancer and undergoing ADT. Mean follow-up was 8.3 years. IADT was used in 16.4% of the population. Men more likely to undergo IADT included those with prior local therapy and those in the highest income quintile. At the provider level, radiation oncologists were more likely to use IADT as were providers with more than 10 years experience.

The data suggested that IADT may be an underutilized strategy, although this study was limited by the typical constraints of using an administrative database. It is often difficult to understand why and how physicians make decisions. Clinical guidelines are quite important as are randomised trials, but adoption can vary according to a number of variables, some of which are poorly understood. The study found:

- Radiation oncologists were more likely than urologists to use intermittent therapy.
- More experienced clinicians were also more prone to intermittent therapy use.
- Patients who had a higher income status were more likely to be treated intermittently, as were patients with prior definitive therapy.

Read more here

## Myocardial Infarction and Stroke Risk with Abiraterone and Enzalutamide in Patients with Metastatic Prostate Cancer

In this retrospective analysis of 6294 men with metastatic prostate cancer who received treatment with ADT and novel antiandrogen agents (abiraterone or enzalutamide), treatment with abiraterone was associated with a 31% increased risk of myocardial infarction or stroke compared with enzalutamide treatment. No difference in incidence rates was observed in patients who switched between novel antiandrogen agents. The data suggested an increased risk of stroke or MI with abiraterone use compared with enzalutamide, suggesting that enzalutamide may be indicated in patients with prostate cancer with a high cardiovascular risk.

Read more here

*If there are other medical articles or areas of interest that you'd like featured in the Walnut, please contact us here.*

Prostate Cancer Foundation of Australia

## 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, other treatments, and potential side effects of treatment, such as incontinence, erectile dysfunction, and coping with hormone therapy. Simply call PCFA on 1800 22 00 99 to be connected with a volunteer.

If you'd like to be a volunteer yourself, read this and then email PCFA here.

## Nubeqa® listed on the PBS!

Nubeqa® (darolutamide) will be listed on the PBS from 1 Nov 21 for patients with non-metastatic castration resistant carcinoma of the prostate.

The PBS listing has been recommended by the independent Pharmaceutical Benefits Advisory Committee and follows to some fantastic lobbying by PCFA. It's great news.

Without PBS subsidy, around 1,000 patients may pay more than $40,000 per year for treatment. Instead, they will pay a maximum of $41.30 per script or $6.60 with a concession card.

Read more here

## Blue Sky News

Download your July 21 Blue Sky News here

Cancer Council ACT

## Cancer Council 13 11 20

Cancer Council's 13 11 20 is a free and 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.

The 13 11 20 service open Monday to Friday, from 9am – 5pm. Outside these hours, you can leave a message and they will call you back.

## Informed financial consent

A cancer diagnosis can be an emotional time for you and your family and requires decisions about the type of care and where to receive care. These decisions can impact on finances so we all want to know what we'll have to pay for treatment.

Informed financial consent requires patients to have information and support to make informed decisions about their care. Cancer Council, with Breast Cancer Network Australia, CanTeen and PCFA, have developed a Standard for Informed Financial Consent to guide discussions between health professionals and patients to discuss the risks and benefits of treatment, including cost.

You should know the total costs for your treatment, other health professionals involved in your care, and where the same or similar benefit can be provided at less cost. If you have private health insurance, you should contact your insurer to discuss if your treatment is covered.

Everyone deserves the chance to make the best decisions for their care, so it is important that you feel comfortable to talk to your healthcare professional about any financial concerns relating to cancer treatment.

Read more here

## Appreciation

Thank you to PCFA, the ACT Government, SHOUT, Southern Cross Club, Chartertech, 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)
- ICON Cancer Centre – Australia (Open)

## 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@pcsg-act.org.au

## Personal support - How can we help you?

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

If you would like immediate support, advice or assistance, please contact: info@pcsg-act.org.au

Alternatively, you can contact the President and Secretary directly:

**President**: Greg McRoberts
Phone: 0413 480 864
Email: president@pcsg-act.org.au

**Secretary:** David Newman
Phone: 0412 812 875
Email: secretary@pcsg-act.org.au

### 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.