



THE WALNUT

SEPTEMBER 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

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



Next monthly meeting

Our annual general meeting and next monthly meeting will be held at 7 pm on **Wednesday 18 September 2019**.

Our speaker will be physiotherapist Maureen Bailey. She will speak about what we need to do to prepare for and recover from prostate cancer treatment and remain healthy after treatment in terms of our physical wellbeing, particularly continence.

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 map](#)).

President's Message

We are saddened to learn of the death of long-time member, Roger Allnutt. A celebration of his life will be held on 25 September (details on page 3). We extend our sympathies to Helen and family.

At our meeting in August, we launched our new [website](#). I hope you have now had an opportunity to have a look at this. We also welcomed Cathie O'Neill, Executive Director, Cancer Ambulatory and Community Health Support at The Canberra Hospital. Cathie told us about the many interesting developments at the Canberra Region Cancer Centre. Thanks Cathie.

I would also like to thank the Holy Family School at Gowrie for again inviting us to attend their annual Father's Day event as its nominated charity. We appreciate the school's continuing generosity. We have also received a similar generous donation from the ACT Masters Hockey Association.

Our next meeting will be our annual general meeting, but this year we will also have an interesting guest speaker, physiotherapist Maureen Bailey. We hope you can attend this meeting.

Annual general meetings are reminders that we need to elect members to our executive committee. Our constitution requires five members on the committee, three of whom are the President, Secretary and Treasurer. However, it is good practice in terms of succession planning to have *ex-officio* members on the committee in addition to the five formal committee members.

This year John Hayhoe will be stepping down as Treasurer and I thank John for the valuable work that he has done. Other members have been on the committee for some years and cannot continue for much longer. So, I encourage all members (men and women) who are interested in the continued role of the Group in supporting members in their prostate cancer treatment journeys to consider nominating for the committee. If you are willing to do so, please complete the [nomination form](#) and email this to Secretary, David Hennessy (secretary@prostate-cancer-support-act.net).

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, the ACT Masters Hockey Association and the many individuals who have assisted in our fund-raising activities.

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, 10 September 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.

Thank you from PCFA Chief Executive Officer

Our Chairman Steve Callister recently asked me what the highlights have been of my first few months in the CEO's Office.



Without question, the highlight has been meeting many of you, our Support Group Members, to engage in direct conversation — sharing information, listening to you talk about your experiences, and learning from your unique insights into prostate cancer and the work of the PCFA.

Our conversations have left me in no doubt that the steady framework we are building from is one you have created. I am abidingly thankful for your contributions.

Harnessing your feedback, I have turned my focus to redoubling our efforts not just to beat prostate cancer, but to ensure that the 211,000 men living with the disease are living well.

Strengthening our connection with you and the community is key to that task.

To this end, we will celebrate Prostate Cancer Awareness Month in September by launching two new ground-breaking initiatives. Both are Australian firsts. The first will be the release of an online Decision Aid for PSA Testing. The second will be the publication of a Position Statement on Screening for Distress and Psychosocial Care for Men with Prostate Cancer, supported by the Monograph: A Psychosocial Care Model for Men with Prostate Cancer.

Both projects have strong support from the Federal Health Minister and Australian peak bodies, which reflects well on our status as a pre-eminent non-profit and trusted source of evidence-based information to improve prostate cancer control. I'll send updates on each of these landmarks in coming days.

My first few months in the CEO's Office have also

allowed me the opportunity to get to know our state and territory staff, boards, and community supporters — strengthening relationships and identifying pathways for growth.

Of course, growth would not be possible without a priority focus on outreach and support. On this note, I am pleased to introduce you to our new Head of Community Outreach and Support, Kath Duggan. Kath is an experienced community health practitioner, having served previously for Cancer Councils and Australian Government Primary Health Networks. Kath will further inspire our work by reinvigorating our approach to supporting you and others affected by prostate cancer.

Finally, it was my great honour recently to present the 2019 Max Gardner Awards for distinguished service to three individual members of the network who have made an outstanding and significant contribution to reducing the impact of prostate cancer on Australian men, their partners, and the community. My congratulations to Mary Jones, Tony Maxwell, and David Merry — we are abidingly grateful for your service, like those before you and those who will follow, to make a difference.

Thank you once again for making me feel welcome — together we can change the game.

Best wishes

Professor Jeff Dunn AO
Chief Executive Officer

Call for nominations for the Executive Committee for the coming year

All members of the Group are eligible for election to the Committee.

Members of the Committee will be elected at the Group's annual general meeting (AGM) at 7 pm on Wednesday 18 September.

All members (men and women) are encouraged to consider nominating for the Committee. We particularly need someone to take on the role of Treasurer.

Members can also join the committee on an *ex officio* basis to help with its work and to become familiar with what is involved in being on the committee.

Any member who wishes to nominate for the Committee is asked to complete the [nomination form](#) and return this to our Secretary, David Hennessy. Nominations must be received before the start of the AGM (although it is helpful to receive nominations as soon as possible). Nominations can be emailed to David at secretary@prostate-cancer-support-act.net.

Meet Jeff Dunn and other PCFA staff

Would you like to meet Jeff Dunn and other PCFA staff at 4 pm on Wednesday 11 September in the restaurant on the 1st floor of the Nishi Ovolo Hotel (former Hotel Hotel)? if so, please urgently provide indication of intention to attend to John McWilliam: president@prostate-cancer-support-act.net

Vale Roger Allnutt

Passed away after a long battle, aged 78 years.

A celebration of Roger's life will be held at the Canberra Southern Cross Yacht Club Marquee, Lotus Bay, Mariner Place, Yarralumla on Wednesday 25 September commencing at 2:30 pm. Please RSVP to olivia@stretchtherapy.net.



Our August Group meeting

Canberra Region Cancer Centre developments

Our speaker at our August meeting was Cathie O'Neill, Executive Director, Cancer Ambulatory and Community Health Support at The Canberra Hospital.

Cathie spoke about developments at the Canberra Region Cancer Centre. The long-term aim is for the Centre to have a comprehensive range of services, similar to cancer centres in other cities, such as the Peter MacCullum Cancer Centre in Melbourne. These services include a wellbeing centre, research hub and state-of-the-art inpatient facilities.

There is a range of known benefits from providing wellbeing services at cancer centres. These include:

- helping to reduce the impact of cancer on quality of life;
- enhanced efficacy of treatments and a reduction in side effects;
- improved health and wellbeing of people affected by cancer;

- more prompt action in the event of symptoms; and
- improved transition to primary health care.

The wellbeing centre will be located on Level 4 of the Cancer Centre. It will not be able to cater for everyone initially and it is important that the services it does provide are of a high standard. Initially therefore services are likely to focus on individuals from the age of 15 years undergoing active treatment in the ACT and surrounding region (30 per cent of cancer patients come from NSW). It will provide evidence-based interventions and will work in partnership with the Australian National University, the University of Canberra and the Australian Catholic University.

Services envisaged at this stage include exercise physiology, education programs (living with cancer, transitioning out of cancer care and caring for people with cancer), evidence-based complementary programs, including oncology yoga, mindfulness and nutrition/cooking programs; and other similar programs. There will be a drop-in centre to facilitate social connection, support and information gathering. Groups, such as ours, may be able to meet at the Centre as



The Wellbeing Centre at the Peter MacCullum Cancer Centre in Melbourne

there will be some group spaces. It will aim to be welcoming.

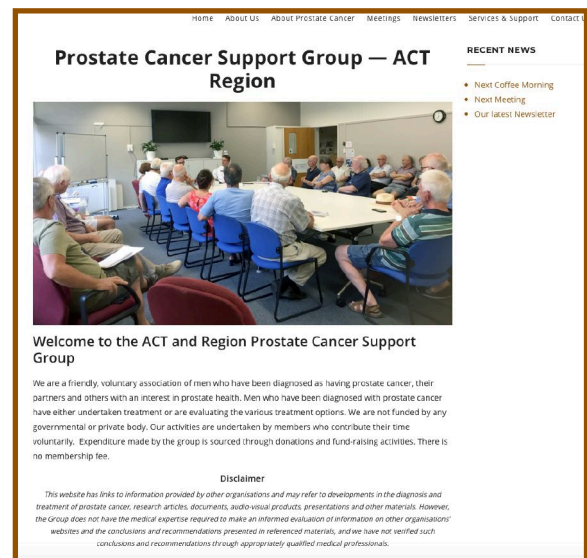
Funding for the wellbeing centre is being met from bequests and other donations and fund raising activities such as the recent Walk for Wellness). Available funding will dictate how quickly the centre will be up and running and what services are provided. However, it is expected that fit-out will be completed by the end of 2020.

The Research Hub will be located on Level 3 of the Cancer Centre and will provide the laboratory and office space to support collaborative research and clinical trials. The ANU has confirmed a contribution of \$10 million towards the hub.

Cathie also told us about progress with in-patient refurbishments at the hospital. Phase 1 is nearing completion and involves a connecting bridge between the Cancer Centre and the wards. These wards (14 A and 14 B) include a clinical trial facility and a positive pressure ward (to help minimise infections). Two new, lead-lined rooms (costing \$800,000) have been completed for thyroid cancer patients using Radioiodine (¹³¹I).

Finally, Cathie told us about the replacement program for the Cancer Centre's linear accelerators. Two of these replacements have been commissioned, with the first coming on line this month (September 2019). There have been some increases in wait times as a result of the replacements, but generally these have been well

managed, for example, with longer hours of operation and careful scheduling of patients.



Our new website

We also launched our new [website](#) at our August meeting.

Thanks to Mike Boesen for his work on the old website over very many years and for his input to the new website. Thanks also to Mark Jardine and John McWilliam for their work on the new website.

The development of the new website has been a major task and we hope that you find it useful.

Suggestions for further improvement are welcome.

September executive committee meeting

At its meeting on 4 September, the executive committee, among other things:

- noted progress with action that is being taken to review the currency of the Group's mailing list and to develop an up-to-date membership list;
- discussed arrangements for the annual general meeting on 18 September;
- discussed arrangements for future monthly meetings, including possible speakers for meetings in early 2020;
- agreed to invite the nurses to whom the Group provided scholarship to undertake specialist prostate cancer nursing studies to speak about their experience and then consider what further scholarships we might offer;
- noted that there had been a successful fundraiser at the Holy Family School, Gowrie and that the ACT Masters Hockey Association had also made a generous donation. Letters of thanks and certificates of appreciation will be sent to both organisations;
- noted that Harness Racing ACT has again invited the Group to be their sponsored charity at their Twilight Racing event on 22 December and that we will again arrange for members to have dinner at the event;
- noted that the audit of the Group's financial statements for 2018-19 has been completed and that no issues have been raised;
- discussed arrangements for the meeting with PCFA representatives on 11 September and for representation of the Group at the NSW Support Group Leaders meeting on 27 November;
- approved arrangements for SHOUT to help support awareness raising about the Group with prostate cancer related medical practices; and
- agreed to seek a volunteer to help with preparation of the Group's monthly newsletter.



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 September 2019 edition of the *PCFA Online Community Digest* has articles on:

- highlights from the Asia-Pacific Prostate Cancer Conference 2019. A focus on patient-reported outcome measures was one of the many highlights ([Read article](#));
- testing for hereditary gene mutations in men with metastatic prostate cancer. Genetic tests for men with metastatic cancer, although recommended, are expensive and are not systematically performed in Australia. Would Australian men with metastatic prostate cancer benefit from genetic tests? ([Read article](#));
- the results of the latest clinical trial results for ultra-hypofractionated radiotherapy (higher doses over shorter periods) for prostate cancer ([Read article](#)); and
- which diet and lifestyle recommendations for men with prostate cancer are supported by science ([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>.

Cancer Counselling Service

Both people with cancer and their families may experience a range of emotions and situations at the time of diagnosis, during and after treatment. The Cancer Counselling Service, funded by ACT Health, can help you adjust to the changes that cancer brings.

Anyone over the age of 16 who has been diagnosed with cancer and family members and caregivers can use the service.

Available support includes:

- individual counselling;
- therapeutic and skills training groups; and
- information and referral to other community services.

You can refer yourself by ringing the Community Health Intake line on 02 5124 9977.

There are two service locations:

- Phillip Community Health Centre, 17 Corinna Street, Phillip
- Belconnen Community Health Centre, 56 Lathlain Street, Belconnen.

Advanced Care Planning Workshop

An Advance Care Health Plan ensures your values and preferences are respected when you can't voice your decisions. This could be due to a stroke, a car accident or other health issue. Learn the steps to make a plan, tips for having the conversation about your wishes and find out who can help to get your plan in place.

Free workshop run by: Health Care Consumers Association (HCCA)

Date: 10:00am - 12:00pm, Thursday
3 October 2019

Venue: Building 1, Pearce Community Centre,
Collett Place, Pearce.

RSVP: by Monday 30 September to
karenjames@hcca.org.au or phone: 6230 7800.
Light refreshments provided.

Cancer Services Nursing Research Priorities Project

Researchers from the University of Canberra and Canberra Health Services would like to know what you think the priorities for nursing research should be.

They are seeking participants for this study who are:

- aged 18 years or over and have been diagnosed with any cancer;
- relatives of people aged 18 years or over who have been diagnosed with any cancer;
- able to participate in a group session in English; and
- have had treatment as either an inpatient or outpatient in the ACT or at one of the regional Oncology/Haematology clinics in Bega, Moruya, Cooma or Goulburn.

Read [further details](#) on what is involved and how to participate.

Webinar invitation: How do I live well with advanced cancer?

If you're living with advanced cancer, how do you keep yourself as physically and emotionally well as you can and maximise your quality of life? In this webinar, we explore strategies for those living with advanced cancer, their carers and health professionals.

Date: Thursday, September 19, 2019

Time: 7 pm to 8 pm AEST

Duration: 60 Minutes

Where: Online - join via your computer, tablet or smartphone

Presenters: Ian Cant, Associate Professor
Craig Gedye and Diana Adams

[Find out more and register](#)

Coming Group events

11 September (4 pm, restaurant on 1st floor, Nishi Ovolo Hotel (former Hotel Hotel))	Meeting with PCFA Chief Executive Officer, Jeff Dunn, and other PCFA staff.
16 October	Monthly meeting. Speaker is medical oncologist, Dr Ganes Pranavan.
20 November	End-of-year informal meeting and celebration.
15 December	Harness Racing ACT Twilight event with proceeds to the Group. As was the case last year, we will have a Christmas dinner at this event and it should again be a most enjoyable occasion and an opportunity for us all to socialise together.

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 members. Any opinions or conclusions expressed are those of the authors. See Disclaimer below.

Exercise medicine for men with prostate cancer

The PCFA has been funding research into exercise as a medicine for cancer. Tailored exercise programs can reduce treatment side

effects, fatigue and anxiety in cancer patients. This is very good news for the 200,000 Australian men living after a diagnosis with prostate cancer, helping to improve their quality of life.

[Watch the video](#) the PCFA has released on this research.

Patient-reported sexual quality of life after different types of radical prostatectomy and radiotherapy

This study compared the sexual dysfunction scores of 835 men who were newly diagnosed with prostate cancer from 2011 to 2013 with the treatments they had received (external-beam radiotherapy (EBRT), EBRT with androgen deprivation therapy (ADT), brachytherapy, nerve-sparing radical prostatectomy and non-nerve-sparing radical prostatectomy. The findings of the study indicate that radiotherapy alone results in the best preservation of sexual function, and brachytherapy provides similar outcomes. Radiotherapy with ADT and nerve-sparing radical prostatectomy yielded similar outcomes, whereas patients treated with non-nerve-sparing radical prostatectomy experienced the worst sexual function.

[Read the study.](#)

Deferred radical prostatectomy after an initial period of surveillance

This study, published in the *Journal of Urology*, evaluated post-prostatectomy outcomes in 448 men who were initially on active surveillance in a single institution over the period 1994 to 2017. The median time of treatment deferment was 27 months.

The authors found that the data suggest that men with at least two cores of grade group 2

disease may benefit from immediate treatment, whereas they found no significant difference in risk for men with one core of grade group 2 disease. However, the authors caution that active surveillance protocols and tools have evolved over the period from which the study population was drawn, and that new tools and techniques, such as multiparametric MRI, genomic risk-stratification tools, and targeted biopsies may affect the treatment decisions of current active surveillance patients.

[Read the study.](#)

New Prostate Cancer Clinical Practice Guidelines

The National Comprehensive Cancer Network released new clinical practice guidelines in May 2019. These include recommendations of germline genetic testing at the time of diagnosis for men with a positive family history. As a higher incidence of germline mutations is found in intraductal cancers, and such mutations can have treatment implications, patients with intraductal prostate cancer should undergo germline genetic testing.

[Read more about the new Clinical Practice Guidelines.](#)

More about germline genetic testing

The latest PCFA Online Community Research blog has an article on germline genetic testing (see link on page 7). The *Journal of Urology* also has an article on this, which is reported in *Practice Update*. It concludes that, while germline genetic testing may inform men and their relatives about prostate cancer risks, there are ongoing challenges. Some of these challenges include a lack of genetic counsellors, affordability/insurance coverage of testing, and how these results ultimately affect testing and treatment. With increased utilisation and interest in genetic risk stratification, the researchers also conclude that more studies are needed on how germline mutations affect systemic therapies in patients with metastatic disease as well as cancer screening in men with germline mutations. [Read article.](#)

The Group notes that testing in Australia would be better performed through a specialised genetic counselling service and may not be Medicare refundable.

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.

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.