



THE WALNUT

MAY 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, 19 May**, where we will be joined by Mr David Dangerfield, who will be talking to us about nerve replacement surgery for treating erectile dysfunction. Our COVID Safety Plan is still 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 8th of June** at the **Jamison Southern Cross Club**.

All are welcome to attend our meetings and coffee mornings,

Our Constitution is now amended!

Thank you to everyone who has been involved in amending and approving the update to our Constitution. It was voted on at our Special General Meeting on the 21st of April and been accepted by the ACT Government.

It's been a long road but we've finally got there, and our amended Constitution now better reflects how we do business and how we can support the needs of members.

The most important changes include:

- **introducing an 'Inactive' membership category** to allow members to reduce their need for and obligations of regular engagement without losing the benefits of membership,
- **allowing online participation** to allow Full members to attend and vote at meetings via Skype and Zoom,
- **allowing proxy voting** to allow Full members to have their say at AGMs, etc, even if they can't attend,
- **improving how your Committee is appointed** to ensure that your vote for/against counts.

Our updated Constitution can be accessed [here](#) and includes [these amendments](#).

Melb Uni PhD support request

Ms Louise Bouchier (louise.bouchier@unimelb.edu.au) is a PhD student at Melbourne University and is researching the sexual health needs of older adults (ie. aged 60 and over) in Australia, via an anonymous online survey.

Older adults have different sexual health needs from younger people and there are very few information sources tailored to older demographics.

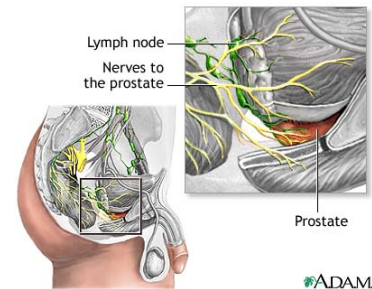
If you would like to participate in the survey, please click [here](#). The survey closes on the 31st of May 2021.

Dealing with Erectile Dysfunction

Erectile dysfunction (ED) is a common concern for those undergoing surgery for prostate cancer, but it can also occur in men who have had radiation therapy or can be age-related. Whether it is temporary or permanent, minor or severe, erectile dysfunction can be quite distressing.

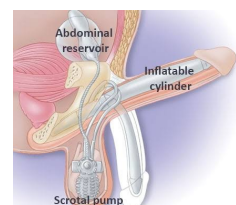
Physiology

- Natural erections are caused by inflow of arterial blood into the penis' central artery, other incoming blood vessels and spongy tissue of the two cigar-shaped corpora cavernosa.
- The nerves controlling erections are very fine and situated close to the prostate. They can be cut, damaged or temporarily traumatised during surgery or by radiation.
- Nerve-sparing surgery attempts to separate prostate tissue from the nerve bundles without damaging them. If the cancer is close to the nerves, they'll likely have to be removed.



Management Techniques

- **Time.....** Even if they aren't cut or removed, it is very common for the nerves controlling erections to be traumatised during surgery and it takes time for them to recover. For some, natural erections can return within months; however, this can take up to two years or more.
- **Drugs.** Cialis and Viagra are often prescribed for rehabilitation post-surgery to improve blood flow to the penis when you are aroused, in order to 'strengthen' a natural erection. They can have side effects so must be used under medical supervision.
- **Vacuum devices.** These use a device to draw blood into the penis via air suction. After the penis has inflated, a band can be used to constrict the blood flow and stop it flowing out, thereby stopping the penis from returning to a flaccid state. Pumps are useful post-surgery to help keep the penis' internal structure elastic in order to reduce the chance of fibrosis (ie. internal scarring) and atrophy (ie. shrinkage).
- **Injections.** Penile injections can generally be self-administered at home. They can help treat ED by improving blood flow to the penis, which leads to firmer erections. An erection should follow an injection within 5 to 15 minutes, and should last about 30 to 60 minutes. Alternating sides each time you inject can help you avoid developing scar tissue.
- **Penile implants.** A penile implant is generally used when all else has failed and requires surgery to replace both corpora cavernosa with inflating devices. Inflatable implants use a fluid-filled reservoir implanted under the abdominal wall, a pump and a release valve inside the scrotum, and two inflatable cylinders inside the penis.
- **Nerve replacement.** This involves connecting a nerve graft to the side of the thigh's femoral nerve, enabling part of the nerve to branch off and grow into the penis where it can restore nerve connections. This will be discussed in our May meeting.



Further detail can be found in PCFA's ['Understanding sexual issues following prostate cancer'](#) publication. Assistance can also be sought from the team at [Men's Health Downunder](#).

Current Activities

Membership database update. As discussed last time, we're almost at the Finish Line 🏁 with this one so thank you to everyone for helping us. It's been a long, but a very necessary, road that we've had to travel, as it has helped us reconnect with a number of our members who we'd previously lost contact with. It has also helped us ensure that our Annual General Meetings and other significant voting activities are lawful and legitimate. It's always a good thing to keep on the right side of the Government, eh? 😊

With the Constitution's amendment now having been approved, 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 but aren't members per se and so have no voting rights.
 - Our Support Network includes urologists, nurses, government officials and representatives of PCFA and Cancer Council.

If you think that you may be in the wrong group (eg. you want to attend and vote at our meetings but aren't getting advice about our upcoming meetings), please email Dave Newman at secretary@prostate-cancer-support-act.net so that we can update your records.

Website update. We are in the middle of rationalising our internet footprint, so that we can simplify how we do business and cut costs. This will provide a couple of immediate benefits:

- **New MS Office licensing.** We use an ongoing monthly membership for Office 365, which allows us to securely store our files on the Cloud but only provides one email address and exposes us to ongoing (but manageable) costs. We are currently applying for a Not For Profit licence, which will reduce costs further and give us more email flexibility.
- **New website address.** Our current website address is a bit of mouthful, don't you think? We're going to change it to something much simpler, which will make it easier for people to find us. In combination with the new MS Office licence, this will also provide us with the ability to streamline our email addresses and make things much easier for you if you need to contact one or more of the Committee.

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 third Wednesday in September this year, so we'd like to start looking for their replacements early.

The Committee has three legislated positions (ie. the President, Secretary and Treasurer) and two (soon to be 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.

Transperineal Prostate Biopsy and Detection of Clinically Significant Prostate Cancer Among Men on Active Surveillance

Transperineal prostate biopsy is an effective method of prostate sampling for detection of cancer, but its comparative effectiveness to the transrectal approach is not well-understood.

A recent study has compared detection rates of clinically significant prostate cancer in men on active surveillance. While limited to men on active surveillance, the study's findings suggested that transperineal prostate biopsies may allow for improved anterior prostate sampling and, thus, improve selection of patients on active surveillance.

[Read more here](#)

Impact of Time to Definitive Treatment on Outcomes for Intermediate-Risk and High-Risk Prostate Cancer

The authors of this systematic review identified 24 articles on outcomes in men with intermediate/high-risk disease who had delays in their treatment. While the quality of evidence was low, the authors found that delays up to 3 months did not change oncological outcomes. Beyond that, data were mixed, with some studies suggesting treatment delays of 6 to 9 months may be associated with worse pathological outcomes and risk of biochemical recurrence. Other studies suggested no difference in outcomes with delays up to 12 months. [Read more here](#)

Comparison of Treatments for Nonmetastatic Castration-Resistant Prostate Cancer

For non-metastatic castration-resistant prostate cancer (nmCRPC), three drugs under patent protection (Apalutamide, Enzalutamide, and Darolutamide) were approved based on randomised, placebo-controlled trials; one drug with generic availability (Abiraterone acetate) showed efficacy in a single-arm trial and is commonly prescribed. Lacking head-to-head trials, the optimal treatment for nmCRPC is unknown, despite widely varied treatment costs.

The authors of this article compared the available treatment options for patients with nonmetastatic castration-resistant prostate cancer. Abiraterone was associated with the lowest risk of metastasis or death compared with placebo. However, when analysed for risk of death only, Darolutamide was associated with the lowest hazard, followed by Enzalutamide and Apalutamide. Darolutamide was also associated with the lowest odds of serious adverse events compared with placebo. [Read more here](#)

Adjuvant Radiotherapy in Node Positive Prostate Cancer Patients

Management of post-prostatectomy patients with node-positive pathology (pN1) remains controversial. In this retrospective cohort study, the authors evaluated outcomes of 187 men with pN1 disease who underwent adjuvant radiotherapy with androgen deprivation. The authors report that receiving aRT with androgen deprivation therapy (ADT) resulted in improvement in a number of clinical endpoints. [Read more 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. 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.

Penile Rehabilitation webinars

You can find a video recording of Michael Gillman's Mar 21 Penile Rehabilitation webinar on PCFA's YouTube channel [here](#).

A second webinar was held on 12 May 21, where Dr Gregory Malone also dealt with the management of erectile dysfunction. It was more focused on surgical interventions and conservative forms of management. You can find it [here](#).

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



**Cancer
Council
ACT**

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.

Travelling for treatment

Cancer Council ACT is interested to learn how people in the ACT region travel to their cancer treatment, and has developed a short survey to hear from people who are currently undergoing cancer treatment, those who have recently finished and/or their family members, friends and carers.

If you would like to help, please complete the following anonymous survey [here](#) and let us know how you get to treatment.

Publication: Understanding Complementary Therapies

This booklet can help you understand more about complementary therapies, which are used in combination with conventional cancer treatment. There are many reasons why people consider using complementary therapies. They may offer physical, emotional and spiritual support, reduce side effects from medical treatment, and improve your quality of life. [Download the publication here](#)

Appreciation

Thank you to PCFA, the ACT Government, SHOUT, Paddywack Promotional Products, Harness Racing ACT, and everyone who has assisted in 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.