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Prostate Cancer Foundation of Australia

THE WALNUT

February 2024

Newsletter of the Prostate Cancer Support Group–ACT Region

Postal address: C/- SHOUT, Building 1, Collett Place, Pearce ACT 2607

https://pcsg-act.org.au

Coming Events

Coffee morning, 10:00 am Tuesday 13 February 2024

Our next coffee morning is at the Canberra Southern Cross Club, Jamison.

Come along and share your experiences with men who have been recently diagnosed with prostate cancer or who are continuing their prostate cancer treatment journeys.

Group monthly meeting, 6:30 pm for 7:00 pm, Wednesday 21 February 2024

Our February Group meeting is being held at our usual location – the Community Room at the Pearce Community Centre, Collett Place, Pearce.

Our speaker for this meeting has yet to be confirmed.

President's Message

Caring for our partners and carers

We all know too well the highs and lows of our prostate cancer journeys.

I think that's its important from time to time to check in on those supporting us.

Sometimes, I think we can get complacent or almost expectant of those around us, without giving enough thought to how our journeys affect them.

In most cases these are the people that are our rocks, the people who remind us its OK, that we can get through this, and that life will continue on.

Maybe its worth just occasionally asking them, "How are you going?"

Remembering to show our appreciation either with a kind word or deed can do a lot to provide support to them.

We are not always at our best during this journey, but having that support person beside us can make all the difference and give us the reason to fight on.

All the best to you, your partners and carers.

Greg McRoberts
President

Our January Meeting

Eighteen people attended our January meeting—a good attendance for the first meeting of the year.

We had an online presentation from Graham Meredith from Tasmania. Ten weeks previously, Graham underwent a novel nerve replacement therapy to address erectile dysfunction. While it is still early days, the signs for him that the procedure has been successful are very positive.

This new procedure, pioneered in Melbourne by microsurgeon Professor Christopher Coombs and urologist Dr David Dangerfield, has been found to achieve success in restoring potency after prostate surgery. A study published in the prestigious urology journal *European Urology* found erectile function was restored within 12 months of surgery for 71 per cent of men left impotent by prostate surgery. Overall, 94 per cent of men in the early study reported 'significant improvements in sexual function'.

The minimally invasive operation works by using nerves taken from the lower limbs to re-establish neural pathways to the penis providing the chemicals that initiate erectile activity. First, a 30cm section of the sural nerve—taken from the calf—is transplanted into the groin. One end of this nerve is grafted onto the main nerve in the upper thigh—the femoral nerve—and the other end is inserted into the penis. This process is performed twice; once on each side of the body.

Over the following months, nerve fibres regenerate on both sides—from the femoral nerves travelling down via the graft into the penis—gradually restoring erectile function.

The novel nerve grafting technique is minimally invasive. It achieves the best rates of restored erectile function after prostate surgery of any surgical procedures currently available, dramatically improving the quality of life of most patients. Seven out of 10 men who undergo this procedure are able to sustain erections for satisfactory sexual intercourse, and the majority enjoy significant improvements in sexual function.

Graham explained his experience with this procedure and how he came to pursue it. Graham's journey, started with tiredness symptoms that he experienced at the age of 54, and which were two years later attributed to prostatitis. This was treated successfully. However, because of other symptoms, further tests were performed, resulting in a diagnosis of prostate cancer and a radical prostatectomy in May 2017.

Graham investigated all of the normally recommended treatments for erectile dysfunction before he learnt about the clinical trial that Professor Coombs and urologist Dr Dangerfield had just completed.

Graham had to travel from Tasmania to Melbourne for tests to ensure that he would be a suitable candidate for the procedure. Normally a man must have had a radical prostatectomy not more than five years previously, although in Graham's case it was more than five years.

To be a suitable candidate, men must not have previously had radiotherapy, hormone treatment, and chemotherapy for the treatment of their prostate cancer.

The only side-effect that Graham said he had experienced to date was pain in the ankle from removal of the nerve there. This is expected to disappear over the coming two years as the nerve there regenerates. This problem may also be overcome in the future because consideration is now being given to using nerves from sheep instead of nerves from the leg.

The treatment is not inexpensive. There was the cost for two surgeons, an anaesthetist, and private hospital costs. In total, Graham outlaid around $21,000 and received Medicare rebates of around $4,000. He also had costs for his accommodation in Melbourne and travel from Tasmania. This cost may fall in the future as the procedure becomes more widely available.

Until recently, the only place in the world

that the procedure could be done was Melbourne. However, Graham understands that Professor Coombs and urologist Dr Dangerfield are now also performing the procedure in Sydney. He also understands that there is now worldwide interest in the procedure.

Graham will be reporting on his treatment outcomes every three months to assist in further evaluating the effectiveness of the treatment.

Graham was very open in his presentation about the many challenges, including many personal challenges, that he had faced in his prostate cancer journey. He would like to see more being done to increase awareness of challenges faced by prostate cancer patients. In particular, he considers that more needs to be done for the partners of prostate cancer patients and on how they and their prostate cancer patient partners can better work together in support of each other.

Graham's presentation was very instructive.

It was also pleasing the most members remained after the meeting for refreshments and socialising.

For more information on this new procedure, check out:

- this Channel 7 news report;
- the following three videos on our colleague, Victoria Cullen's YouTube channel - A Touchy Subject.

  New procedures for erectile dysfunction - Part 1

  New procedures for erectile dysfunction - Part 2

  New procedures for erectile dysfunction - Part 3

As always, we stress that "sex" is what you and your partner both agree on. Keeping healthy intimacy in your relationship(s) is what really matters and that takes communication, love and persistence.

ACT Seniors Card Directory

The ACT Seniors Card Directory for 2023–25 is now available. The ACT Seniors Card offers discounts on goods and services from businesses across Canberra, as well as ACT Government concessions.

Click this link to download the Directory.

Executive Committee

Members are welcome to attend meetings of the Executive Committee. If you would like to do this, please contact: secretary@pcsg-act.org.au.

The next executive committee meeting will be held on Thursday 8 February 2024.

PCFA News

This information is taken from PCFA newsletters and press releases

Prostate charity Chairman receives Australia Day AM

Prostate Cancer Foundation of Australia's National Chairman, Adjunct Associate Professor Steve Callister, has been named a Member in the Order of Australia.

The distinguished recognition was announced by Australia's Governor-General as part of the Australia Day 2024 Honours List.

The award recognises Adjunct A/Prof Callister's service to Prostate Cancer Foundation of Australia and men impacted by prostate cancer, as well as his contribution to business.

Beginning as a Support Group convenor, he was appointed Chairman of the charity's Marketing and Fundraising Committee in 2009, rising to the role of Deputy National Chairman in 2015 before taking on the responsibility of National Chairman in 2018.

A/Prof Callister has also just been appointed the inaugural Chair of PCFA's Future Fund Committee, which will oversee the organisation's strategy to significantly boost funding for prostate cancer research between now and 2030.

A/Prof Callister was instrumental in establishing PCFA's Telenursing Service and Prostate Cancer Counselling Service.

We congratulate A/Prof Callister on the recognition of the valuable work that he has been doing for the PCFA and for men affected by prostate cancer.

New PCFA Ambassador: Australian cricket great tells men to get checked

Australian cricket great Tim May has become an Ambassador for PCFA, giving an emotional interview to Channel Seven about his diagnosis with prostate cancer. The former off-spinner and previous CEO of the Australian Cricketers' Association and Federation of International Cricketers' Associations has advanced prostate cancer and is continuing with chemotherapy treatment. He has joined PCFA in urging Australian men to get a PSA blood test and be vigilant about their prostate health, with only 36% of prostate cancers detected at Stage 1 in Australia.

PCFA launches pledge against prostate cancer

With prostate cancer being the most commonly diagnosed cancer in Australia, and with rates of diagnosis expected to rise, the Prostate Cancer Foundation of Australia is calling on men and women to take the pledge against prostate cancer via pcfa.org.au/pledge

Pledge participants will receive a free information kit about prostate cancer screening and early detection.

PCFA Chief Executive, Anne Savage, said the campaign aims to reduce the high number of men who are diagnosed in later stages once the cancer has spread.

"We know through research that, if we detect prostate cancer early, we can beat it, given that the five-year relative survival for prostate cancers detected at Stage 1 is nearly 100 per cent.

"Almost 4,000 Australian men are newly diagnosed each year with Stage 3 or 4 prostate cancers, which are lethal, contributing to more than 3,700 deaths each year."

Men can request a bulk-billed PSA blood test from their General Practitioner, who can refer patients to a specialist for more tests if the results suggest a problem.

The current guidelines recommend men with a family history of prostate cancer consider annual PSA testing from the age of 40. Men with no family history and no symptoms should consider testing from around the age of 50.

For more information about the campaign, go to pcfa.org.au/pledge.

ACT Government | Canberra Health Services

World Cancer Day Program 2024

Free online talks for consumers and health professionals

Navigating the fear of cancer's return

Online talk open to all: Tuesday, 6 February 12.30 –1.30pm

Empowered choices: exploring the consumer's role in cancer research and clinical trials

Online talk open to all: Thursday, 8 February 12.30 –1.30pm

Scan to register for these events or visit: eventbrite.com.au

canberrahealthservices.act.gov.au/wcd

Close the care gap

World Cancer Day 4 February

worldcancerday.org

WHAT THE PROGRAM IS

Taking unused leftover male pads/continence products from men who do not need them anymore and giving them to men in need.

NEED PADS?

Call ahead to check availability and pick-up / appointment times **1300 006 438**

HAVE LEFTOVER / EXTRA PADS?

Drop off any leftover or extra pads to the below locations

INITIATIVE PROUDLY SUPPORTED BY

MENS HEALTH DOWNUNDER

Southside Physio

MENS HEALTH DOWNUNDER DEAKIN

Suite B3 Canberra Specialist Centre
161 Strickland Crescent
DEAKIN ACT 2600

Monday - Thursday
9am - 4pm

SOUTHSIDE PHYSIO WODEN

Unit 3 - Level 1 Canberra Health Point Building
16 Wilbow Street
PHILLIP ACT 2606

Monday - Thursday
7am - 7pm
Friday 7am - 3pm

PROSTATE CANCER SUPPORT GROUP ACT

Shout Building Pearce Community Centre
3 Collett Place
PEARCE ACT 2607

At coffee mornings or meetings

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.

Medicare Item numbers for PSA testing from 1 November2023

Effective from 1 November 2023, the Medicare Benefit Schedule requirements for prostate-specific antigen (PSA) testing have changed.

The new items better align with the NHMRC-endorsed guidelines put forward by the Prostate Cancer Foundation of Australia and the Cancer Council of Australia in 2016.

The general recommendation is for those men who decide to have PSA tests to assist in the early detection of prostate cancer to have a PSA blood test every two years from age 50 to 69 years.

PSA testing may also be useful in other situations, such as prostatitis and in the follow-up of patients with known prostate disease.

The importance of having a significant family history of prostate cancer is also recognised in the guidelines.

The percentage Free PSA can also be helpful in evaluating a raised PSA and in the management of known prostate disease.

Read more about the new items descriptors for PSA.

2023 Top Story in Prostate Cancer: PARP Inhibition Moves Forward

An opinion piece By Oliver Sartor MP on the top prostate cancer story in 2023 was published in the Journal *Oncology* (12 December 2023). Several studies relating to Poly (ADP-ribose) polymerase (PARP) inhibitors were identified in this article.

A PARP inhibitor is a type of prescription drug that helps treat certain types of cancer. It blocks the PARP enzymes in cells.

After his review of the trials, Dr Sartor concluded that the risk/benefit ratio of PARP inhibitors in non-selected patients is not sufficient to justify their use. However, the activity of a PARP inhibitor in combination with with a second-generation androgen-receptor pathway inhibitor (ARPI) such as abiraterone, enzalutamide, darolutamide, or apalutamide is quite substantial for the front-line treatment of patients with metastatic castrate-resistant prostate cancer with a BRCA mutation. In fact, the observed hazard ratios for radiographic progression–free survival are among the best ever reported in prospective trials. Precision medicine works when patients are properly selected.

Read the full article.

Timing of Adjuvant Radiotherapy Following Radical Prostatectomy

Another opinion piece by Dr Sartor in the journal *Oncology* (11 November 2023) reviews the RADICALS-RT study, which examined the optimal timing of radiotherapy after radical prostatectomy.

This study found that there was no advantage to giving adjuvant radiation. The overall survival at 10 years was 88% versus 87%. And the freedom from metastatic disease at 10 years was 93% versus 90% – no difference. On the basis of the study, Dr Sartor argues that waiting until PSA relapse is perfectly appropriate for patients after radical prostatectomy; that you do not have to use adjuvant therapy.

Dr Sartor also noted that urinary incontinence and faecal incontinence were worse with adjuvant radiation therapy.

Read the full article.

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@pcsg-act.org.au

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: Greg McRoberts, president@pcsg-act.org.au 0413 480 864
Secretary: John McWilliam,secretary@pcsg-act.org.au 0416 008 299

Appreciation

Thanks to all those supporting the Group's fund raising activities, in particular, Harness Racing ACT, the Canberra Southern Cross Club, ACT Masters Hockey, Chartertech ACT, Paddywack Promotional Products and SAC Tyrepower, Belconnen.

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@pcsg-act.org.au

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.