



Newsletter **November 2018** – Issue 179

Next Meeting: **Tuesday 20 November 2018**

Prostate Heidelberg provides information, education and support for those affected by Prostate Cancer. At our meetings we:

- Show respect to members, speakers and guests.**
- Allow people to speak and other attendees to listen.**
- Respect confidentiality.**

Next Meeting Tuesday 20/11/18

General Discussion. This is an opportunity for new members to introduce themselves and discuss their PCa journey, and for existing members to provide updates if applicable.

Guest Speaker Tuesday 18/12/18

A/Prof Nathan Lawrentschuk
“How genetics is impacting therapy now and in the future.”

Associate Professor Nathan Lawrentschuk is a urological surgeon and oncologist in the UroOncology Service at the Peter MacCallum Cancer Centre. He also has appointments at The University of Melbourne, Department of Surgery and Olivia Newton-John Institute for Cancer Research at the Austin Hospital, Melbourne

Guest Speaker Tuesday 19/2/19

Cathie Pigott, Project Manager,
Advance Care Australia

More details in next newsletter.

Last Meeting Guest Speaker **Dr Renu Eapen**

Dr Eapen visited us on 16 October to discuss 2 common side effects arising from standard PCa treatments and address the question – must we put up

with Erectile Dysfunction and Incontinence. Her answer was a resounding **“No!”**

Erectile Dysfunction (ED)

ED is common in the general male population, and it is estimated that over 50% of men aged 60+ are affected.

Unfortunately many of the standard treatments for PCa contribute to this problem and the incidence of ED is much higher in the sub-population of men with PCa.

Dr Eapen presented the ED ‘Treatment Algorithm’ and told us that treatment starts with least invasive approaches graduating to more invasive only as required.

1. Lifestyle changes
 - a. Avoid alcohol and smoking.
Manage weight and avoid obesity
 - b. Optimise management of chronic diseases that contribute to ED, such as high blood pressure, diabetes and heart disease.
 - c. Address any relationship issues and seek counselling if necessary.
2. Oral medications: Viagra, Cialis and Levitra.
3. Penile injections and vacuum devices
4. Penile implants

There are many options available, but there is no one single answer for every man. It is up to each of us to pursue appropriate treatment with our doctor and/or specialist to get satisfactory results.

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Incontinence.

Incontinence is also a common side effect of standard treatments, particularly radical prostatectomy. While 90% of men will remain dry in the long term, 10% of men will continue to wear pads and 3-5% of men will require more invasive treatment.

Pelvic Floor Exercises. If you are scheduled for radical prostatectomy, your urologist should refer you to a continence physiotherapist. Ideally, exercises should start before surgery.

Behavioural approaches. It is critical to keep a bladder diary to record intake of all fluids and amounts of fluid voided.

Affected men should minimise bladder irritants (coffee, alcohol and spicy food) and avoid excessive fluid intake, particularly before bed. Stop smoking, lose weight and avoid constipation.

Manage Leaking Urine. Pads/ diapers. Condom catheter. Penile Clamp.

Medication. Anticholinergics are useful if incontinence is linked to an over-active bladder.

Surgical solutions. Male urinary sling. Artificial urinary sphincter.

As with ED there are many treatment options and you should consult with your doctor or specialist to determine the best approach for yourself.



Committee Member Barry Elderfield thanks Dr Eapen on behalf of Prostate Heidelberg.

Keytruda availability on PBS

November is Lung Cancer Awareness Month and from 1 November patients with advanced lung cancer will have the treatment Keytruda® subsidised for first-line treatment of metastatic non-small cell lung cancer (NSCLC).

Without PBS subsidy it would cost over \$11,300 per script or \$188,000 a year. Patient will now pay a maximum of \$39.50 per script or just \$6.40 per script for concessional patients, including pensioners.

This listing means that for the first time eligible patients with advanced lung cancer can avoid chemotherapy and be treated with this novel immunotherapy treatment Keytruda®. It will benefit around 850 patients a year.

Keytruda® is an immunotherapy medicine working with a patient's own immune system to recognise cancer cells and destroy them. Clinical trials of Keytruda® for lung cancer has shown that some patients became virtually cancer free after treatment.

This medicine is already listed on the PBS for classical Hodgkin's lymphoma and unresectable Stage III or Stage IV malignant melanoma.

At this time Keytruda® is not available for treatment of Prostate Cancer. but it is now being tested for men with advanced disease – if it works, we should then be able to access it at an affordable price.

Making Zytiga Cheaper

The debate relating to dose rates for Zytiga has intensified – changes to dose rates will make the treatment available at a quarter of the current unsubsidised cost which is approx \$7,800 per month.

It appears that we are being ripped off and Prostate Heidelberg should be part of this

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debate. Any members interested in making representation to the Minister for Health should contact committee member Barry Elderfield.

Meanwhile in the USA, a federal court in New Jersey invalidated the last remaining patent held by Johnson & Johnson on their formulation of abiraterone acetate (Zytiga).

In theory, this means that generic formulations of Zytiga could become available as early as October 31. However, J&J has said it is going to appeal this most recent decision, and the U.S. District Court Judge has therefore stated he wants to consider delaying the availability of generic forms of Zytiga until an appeals court rules on the patent. Quite how long this might take is not clear.

The one thing that we can be quite sure about is that J&J will continue to seek to delay access to generic versions of Zytiga for as long as the company can manage. It is known that Zytiga had sales of \$1.4 billion in the first 9 months of 2018 in the US alone.

Living With Advanced PCa Education Program – ONJ Centre, September 2018

In recognition of International Prostate Cancer Awareness Month, ONJC ran their inaugural education session - a special program for men with advanced prostate cancer.

Speakers including our very own Barry Elderfield discussed a number of key topics

- [What is advanced cancer](#) and how treatment decisions are made
- The various symptoms, [cancer treatments and side effects](#)
- The doctor-patient relationship
- How to access the [cancer services](#) available

- Information on important factors like [diet](#) and [exercise](#)
- Myths about cancer
- Relationships, self-esteem and body image
- Coping with loss and grief

There was high turnout on the day and excellent feedback from all attendees. These type of sessions provide critical information to men with Prostate Cancer, we hope that ONJC will be able to run more sessions and we will provide forward advice on any planned dates.

Focus on Clinical Trials.

Clinical trials are vitally important to prove the efficacy and safety of the drugs prescribed to us daily by our doctors. But did you also know that cancer patients who participate in clinical trials have a longer Overall Survival due to access to new therapies before official regulatory approval (which often takes years).

Each month we will highlight a different trial. This month's feature trial is

Galahad – Use of PARP inhibitors to treat Prostate Cancer

The association of BRCA1/2 gene mutations with breast and ovarian cancer reached wide public recognition following the decision by Angelina Jolie to have a pre-emptive double mastectomy following a positive test for these mutations. There is now evidence that BRCA mutations in men are similarly associated with prostate cancer.

Given this common association, it is reasonable to think that treatments for breast/ovarian cancer might also be useful for Prostate Cancer for men who test positive for BRCA1/2 mutations.

Niraparib is one of a number of drugs that act as PARP inhibitors, a type of drug that has been shown to induce apoptosis in cancer cells with BRCA1/2 mutations. It is

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currently approved to treat ovarian, fallopian tube and peritoneal cancer in the USA and Europe (but not in Australia). The main purpose of the Galahad trial is to see if niraparib is useful to treat men with advanced prostate cancer. The safety of niraparib will also be studied. Study sites include Peter MacCallum in Melbourne plus other hospitals in capital cities and regional centres. Recruitment is underway.

For more information see

<http://www.australiancancertrials.gov.au/search-clinical-trials/search-results/clinical-trials-details.aspx?TrialID=NCT02854436&ds=2>

Website 'Gather My Crew' making it easier to get the help you need



Charity organisation Gather My Crew is using community-building technology to help people coordinate support in difficult times. Garnering the support of friends and family, the free Gather My Crew website and online tool is reducing the reliance on already stretched government organisations and local community agencies.

Developed by psychologist and researcher Dr Susan Palmer, Gather My Crew is a digital rostering tool for families 'doing it tough'. The digital tool empowers families to take back control when life becomes chaotic and build their own communities of meaningful support to get them through tough times.

'We want to encourage the broader community to think differently about what they can do to help friends, family, neighbours and colleagues who are going through tough times. Gather My Crew is more than just a rostering tool, it is a community building movement', Dr Susan Palmer, Founder & CEO. Since launch in July 2017, it has been used by over 6,000 people experiencing difficulties such as major illness, accident, stroke and sudden death of a loved one. These users have created over 20,000 tasks that are being done by people within their own support network.

Gather My Crew can be used to coordinate a team of known helpers to assist with things like:

- jobs around the home
- medical appointments
- daily chores
- transport
- arranging an outing.

While working as a psychologist, Dr Palmer regularly witnessed the breakdown between a family in need of help and their support network who were eager to provide support. She realised that barriers preventing people from receiving the right kind of help from their support network included not knowing what help they need or how to ask for it friends and family not knowing how to best help and not wanting to 'intrude' finding it complicated and time-consuming to coordinate ongoing support.

Gather My Crew overcomes these barriers by making it easy to coordinate help from friends and family. As shared by a Gather My Crew user, 'Gather My Crew makes it so much easier to ask for help without feeling like you are putting others out'. Using the online tool, people needing help ('Gatherers') identify the help they need via a 'click and select' list of tasks. They then invite their personal network, or 'Crew', to lend a hand. The help requested and provided is coordinated through an interactive calendar that is visible to the Gatherer and their Crew members.

As shared by user Ian, 'We have started to use Gather My Crew to support my wife

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through her chemo treatments. Thank you for your wonderful site'.

For more information or to create a free account visit

www.gathermycrew.org

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Committee

Max Shub, Facilitator 0413 777342
Barry Elderfield, Treasurer
Janis Kinne, Membership
Spiros Haldas, Library
David Bellair, Web site
Paul Yates, Newsletter

2019 Meetings: 10:00am -12:30pm

Tues 19 Feb Guest Speaker Cathie Pigott
Tues 19 Mar
Tues 16 Apr
Tues 21 May
Tues 18 Jun
Tues 16 Jul
Tues 20 Aug
Tues 17 Sep
Tues 15 Oct
Tues 19 Nov
Tues 17 Dec including Xmas lunch

Internet Resources

Use the internet to find questions to ask your specialist. It should not be trusted to find answers for your personal case. The web is general. Your specialist specifically knows you.

Our members have found the following **websites** to be useful.

Prostate Cancer Foundation of Australia

For guides and help.

www.PCFA.org.au

Australian Cancer Trials

Information on the latest clinical trials in cancer care, including trials that are currently recruiting new participants.

www.australiancancertrials.gov.au/

USA Prostate Cancer Foundation (Guide)

PDF guide for men newly diagnosed with prostate cancer

www.PCF.org/guide/

Us TOO International PCa Education (USA)

USA Prostate Cancer support groups information and newsletter.

www.UsToo.org

Cancer Council Victoria

For general help and to understand services supporting men with cancer.

www.CancerVic.org.au

Ex MED Cancer program

A Melbourne-based best-practice exercise medicine program for people with cancer.

<http://www.EXMedCancer.org.au/>

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ProstMate (PCFA)

www.ProstMate.org.au

The companion for those impacted by prostate cancer, particularly to record all your results.

Beyond Blue

www.BeyondBlue.org.au

HELPLINE – 1300 22 4636; *for help with depression or anxiety.*

Continence Foundation of Australia

www.Continence.org.au/

HELPLINE – 1800 33 0066. *For assistance with incontinence and for aids (such as pads).*

Australian Advanced Prostate Cancer Support Group www.JimJimJimJim.com

For men diagnosed with advanced metastatic prostate cancer.

PCRI Prostate Digest (USA)

<https://pcri.org/insights/>

Prostate Cancer Research Institute supports research and disseminates information that educates and empowers patients, families, and the medical community

PAACT Newsletter (USA)

<http://paact.help/newsletter/>

Patient Advocates for advanced Cancer Treatments.

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