

Prostate Heidelberg

cancer support group

Information, Education and Support for men and their families

Newsletter No. 177

Next Meeting Tuesday 18th September 2018

Prostate Heidelberg provides information, education and support for those affected by prostate cancer.

At the meetings, we:

Show respect to Members, Speakers, and Guests.

Allow people to speak and the other attendees listen.

Respect confidentiality.

The guest speaker at our last meeting was Gina Akers with a very insightful talk on Survivorship. Here is a summary

Cancer Survivorship

Gina Akers, Cancer Strategy and Development, Department of Health and Human Services.

Cancer is a leading burden of disease in Victoria with 90 new diagnoses each day. One in two people in Australia will have developed cancer by age 85. Survival rates have improved markedly over the past years, with 68% of Australians diagnosed with cancer still alive after five years. The most common cancers include prostate, breast, bowel, melanoma and lung cancer. These account for around 60% of all new cancers diagnosed in Australia.

Survivors face a number of issues including impact on work, study, caring roles and finances, persisting side effects (physical, emotional, psychological) and may have varied reactions to completing treatment.

Issues surrounding survivorship have been recognised internationally over the last 15-20 years. However, we are still in the early phases of acknowledging and addressing survivorship needs of people after a diagnosis and treatment of cancer.

Core components of survivorship care include:

1. Prevention and detection of cancer
2. Surveillance for recurrence or for new cancers
3. Interventions for the consequences of cancer and its treatments
4. Co-ordination between oncology specialists and primary care providers

It is recognised that there is significant variation in the individual experiences and a number of people have unmet needs following completion of treatment.

The [Victorian Cancer Plan 2016-2020](#) aims to improve outcomes for Victorians through new models of care through the [Victorian Cancer Survivorship Program](#), support the development of resources and guidelines (e.g. [Optimal Care Pathways](#)), workforce development and survivor self-management.

Survivorship Care Plans are one way of improving survivorship care. These are written documents provided to patients and their GP's, including a treatment summary, follow up tests and schedule, a list of symptoms to watch out for and report and may include a wellbeing plan (things to do to look after self). More information on survivorship care plans can be found here https://www.petermac.org/sites/default/files/ACSC_FactSheet_SCP-howtouse.pdf

Exercise is increasingly seen as having an important role in cancer survivorship. Benefits include:

- Improve physical and emotional health
- Manage weight
- Maintain muscle
- Reduce risk of heart attack
- Keep bones strong
- Help with balance
- Improve sleep
- Reduce anxiety and fatigue

The [COSA exercise guidelines](#) released in April 2018 recommend resistance training (minimum 3 times / week) and aerobic exercise (150 minutes per week).

Thank you Christopher.

It is with regret that we advise that Christopher Ellis has resigned from the steering committee of Prostate Heidelberg. For 6 years Christopher was always the 'common sense' of the steering committee, he will be sorely missed.

2018 SUBSCRIPTIONS \$10

The 2018 annual subscriptions are due from 1st January 2018. The rate is **\$10 per individual, couple or family**. Pay at your next meeting, by mail or directly into the Prostate Heidelberg bank account: BSB 083-256; Account 583244292 (include your name in the details).

Participation in a patient support group increases prostate cancer patient knowledge

A newly published study from a group of German researchers examined the degree to which participation in patient support group activities increased prostate cancer patients' health literacy and, specifically, their prostate cancer specific and non cancer specific knowledge about health care.

Unlike a lot of studies in this area, which often enroll only small numbers of patients, [this study by Haack et al.](#), at Hannover and Hamburg in Germany, enrolled nearly 600 participants in total, so the results should be pretty reliable. Here are the basic data from the study:

- There were 576 participants in total
 - 441 were prostate cancer support group members (Group A)
 - 135 were prostate cancer patients who had **not** participated in a support group (Group B)
- Compared to the patients in Group B, the patients in Group A had:
 - Greater knowledge about prostate cancer in general (odds ratio [OR] = 2.2)
 - Heard about specific guidelines related to prostate cancer (OR = 3.7)
 - Actually read one or more guidelines (OR = 5.1)
 - Greater competence regarding navigation of health services (OR = 1.8)
- Patients in Group A and Group B had similar levels of knowledge about non-cancer-related health care knowledge.

We should emphasize, of course, that one can become very knowledgeable about prostate cancer and how health care systems work without every actually participating in a patient support group of any type (prostate cancer-

specific or otherwise). However, on the other hand, the authors conclude that participation in a prostate cancer-specific support group seems to

provide an important platform for information exchange in the field of [prostate cancer]. The potentially conflicting results on PC knowledge and the application skills may arise from the different forms of measurement — knowledge was tested, skills were self assessed.

What this study did not test, however, is whether the benefits of participation in "live" prostate cancer support groups that meet on a regular basis was any more beneficial than participation in the various (and evolving) forms of on-line and phone-based support groups, and the degree to which participation in support groups increased the probability that patients would choose forms of management (over time) most suited to their individual needs

\$1.3 million to address prostate cancer and male infertility

9 August 2018

The Turnbull Government will provide medical research funding for prostate cancer and infertility, marking the first step towards a new National Male Health Strategy.

The National Male Health Strategy 2020 - 2030, aims to improve the health and wellbeing of all men in Australia over the next decade, especially those at the greatest risk of poor health. Experts in male health, representatives of disadvantaged populations and peak medical bodies met in Canberra today to develop the new ten year plan.

Together we identified key issues and priorities to help us improve the health outcomes for men across the country.

Two National Health and Medical Research Council grants totalling \$1.3 million will go towards new approaches for prostate cancer and research into understanding male infertility. Professor Melissa Southey at Monash University is working on a new way to manage prostate and breast cancer using precision medicine, which will substantially improve health

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outcomes. Prostate cancer is the sixth leading cause of death for males. It is also the most common cancer among men, with more than 16,000 cases diagnosed each year.

Only recently the Turnbull Government created a new Medicare item for the 26,000 men who need a prostate cancer MRI each year.

The University of Newcastle’s Professor Brett Nixon is working to improve our understanding of sperm function and the causes of male infertility. His work will be used to develop innovative therapies to help the one in 35 men with a fertility issue.

We know that men have different health challenges to women, and that their outcomes are often worse. “Almost 50 per cent of men have one or more chronic illnesses including back problems, arthritis, asthma, cancer, diabetes, cardiovascular disease, chronic obstructive pulmonary disease or mental health conditions.

Coronary heart disease, lung cancer and dementia remain the leading causes of death for men, while nearly one in two men will experienced a mental health condition in their lives. Despite these statistics, men are less likely than women to seek help.

The ten year strategy will aim for equal health outcomes for all population groups at risk of poor health.

MRI scans now refundable under Medicare

Not everyone is eligible for MRI’s on Medicare, they can only be ordered by urologists and oncologists

- GP’s cannot order MRI under Medicare
- Only licensed Imaging centres are eligible for Medicare rebates so check with your clinician first

Prostate Cancer Health and Fitness Online: The development and pilot testing of an internet physical activity program for prostate cancer survivors.

Lead investigator

Dr Camille Short for the Freemasons Foundation Centre for Men’s Health. School of Medicine, University of Adelaide.

Summary of project

Research has shown that participating in physical activity is beneficial for prostate cancer survivors. Some men have expressed interest to use the internet as a way to find information on their own. This PhD student project asks whether an internet program could be a good way for men to receive information about physical activity.

The aim of this study is to evaluate the website. To do this, we will randomise people into the main website program or into the control website program for a period of 4 weeks. This is to ask if our program is any better than the cancer and exercise information already out there on the internet. Those who are randomly placed into the control group can have access to the main program after 4 weeks.

Our website will give personally tailored advice to you, provide examples of exercises one can do from home as video tutorials or as pictures, act as an activity tracker. You can submit questions to our “frequently asked questions” to our exercise physiologist who will give video response. It will not cost any money to participate.

Ethics approval

Ethics approval has been granted through the University of Adelaide Human Research Ethics Committee.

Who is this study for?

You may be eligible for this study if you:

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**Prostate Cancer Health and Fitness
Online: The development and pilot
testing of an internet physical activity
program for prostate cancer survivors.**

- Have been diagnosed with localised or locally advanced prostate cancer
- Have had and completed active treatment for prostate cancer (surgery, radiotherapy, brachytherapy) and are in remission
- It is OK to be on hormone treatment and participate
- Can read and understand English fluently
- Have no medical issues that might stop you being active (please speak to your doctor if you are unsure whether you should participate)
- Have access to a computer with internet speeds capable of video content.

The oncological guidelines say you need to do 2.5 hours of cardio-based activity AND two or more strengthen sessions a week.

If you are not currently doing one or both of the components, then you can do the program.

Exclusion criteria:

- Those with metastatic cancer
- Those with localised cancer who are on active surveillance

If you are interested in this study, please contact:

Ms Amy Finlay

Phone: (08) 8128 4056

Email: amy.finlay@adelaide.edu.au

Note: Amy is out of the office on Wednesdays.

STEERING COMMITTEE

Barry Elderfield,	Treasurer
David Bellair,	Website
Janis Kinne,	Membership
Max Shub,	Facilitator
Ph. 0413 777 342	
Patrick Woodlock,	
Spiros Haldas,	Library

CALENDAR 2018

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

Tues 18 Sep'18 General Discussion

Tues 16 Oct'18

Dr Renu Eapen
"ED and Incontinence: do we need to put up with it?"

Dr Renu Eapen is a Consultant Urologist in the Genitourinary Oncology service at the Peter MacCallum Cancer Centre. She also has appointments at the Austin Hospital and Olivia Newton-John Cancer Centre.

Tues 20 Nov'18 General Discussion

Tues 18 Dec'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 Uro-Oncology 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

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Use of the internet is to find your 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. The following are web sites members have found useful:

Organisation	Details	Website
Prostate Cancer Foundation of Australia	<i>For guides and help.</i>	www.PCFA.org.au
Prostate Cancer Foundation (USA)	<i>Guide for men newly diagnosed with prostate</i>	www.pcf.org/guide/
Us TOO International PC Education	<i>USA Prostate Cancer support groups and information</i>	www.UsToo.org/Read-Educational-Materials
Cancer Council Victoria	<i>For general help and to understand services supporting men with cancer.</i>	www.CancerVic.org.au
Ex MED Cancer program	<i>A best-practice exercise medicine program for people with cancer.</i>	www.EXMedCancer.org.au/
Prostmate	<i>The companion for those impacted by Prostate Cancer</i>	www.ProstMate.org.au
Beyond Blue	<i>For help with depression or anxiety. HELPLINE – 1300 22 4636</i>	www.BeyondBlue.org.au
Continence Foundation of Australia	<i>For assistance with incontinence and for aids (such as pads). HELPLINE – 1800 33 0066</i>	www.Continence.org.au/
Australian Advanced Prostate Cancer Support Group	<i>For men diagnosed with advanced metastatic prostate cancer.</i>	www.JimJimJimJim.com
Commonwealth site for palliative care	<i>Government information on palliative care.</i>	www.Health.gov.au/PalliativeCare
Banksia Palliative Care	<i>Specialist home based community palliative care service for people living in the north east suburbs of Melbourne</i>	www.BanksiaPalliative.com.au
University California San Francisco	<i>One of the leading Prostate Cancer Research centres</i>	www.urology.ucsf.edu/patient-care/cancer/prostate-cancer

Useful Newsletters

PAACT Newsletter	www.paact.help/newsletter/
PCRI Prostate Digest	www.pcri.org/insights-blog/2018/04/prostate-digest-volume21-issue1
US TOO Hotsheet	www.ustoo.org/Read-the-HotSheet-Newsletter

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