



Below the Belt!

Vol. 21 No. 2

March – May, 2022

Newsletter of The Nepean / Blue Mountains Prostate Cancer Support Group Inc.
(ABN No. 35 871 442 176)

Well, what crazy times we are living in.....

To any of our Members who are directly impacted by the ongoing flood situation in the Nepean / Hawkesbury area and the North Coast our thoughts are with you.

As you are aware, we had a last minute cancellation of our February Group Meeting. We were advised at about 5.30pm on the day of the meeting that the Emu Sports Club had suffered damage in the terrible storm that moved through Western Sydney on Monday afternoon. As well as suffering water damage the club was without power and therefor had to be closed.

We received this information from one of the club's staff phoning from her own home as the club was completely blacked out! - I was unable to send out a late email to Members as we were also without power!

On a brighter note, we have received notification that the Emu Plains Lions Club has again agreed to sponsor our group's web site. Many thanks to the Lions members (See the banner at the foot of this page)

What's to Come

Group Meeting – Monday March 21st

Jodie McMurray
Clinical Trials

Group Meeting – Monday April 18th

To Be Advised

Group Meeting – Monday May 16th

To Be Advised

Meetings are now held at the Emu Sports Club (Home of Leonay Golf Club)
Gather at 6-30pm for a 7-00pm start.



Our Web Site www.prostatesupport.org.au is now sponsored
by the Members of Emu Plains Lions Club

LIVE WITH IT, DON'T DIE FROM IT

(This article was sent to me by one of our Members – Well worth a read.)

The human body is amazing, it bends and breaks, it mends, it grows. We take it for granted everyday because our life rules what our body does.

Everybody knows somebody who has or had cancer.

Some for a short time like me, some for a long long time.

There are many types of it and many people who can help you with it.

For example I know a very nice couple, Allan and Carol who are happy and helpful with other oldies like us and he has prostate cancer for no reason whatsoever like many of us.

Also there is Cathy a medical professional who gives to others and shows others how to give. She has breast cancer.

Some repair treatments are painful and life changing but successful for our body to mend over time.

I know some people go through hell with medical issues but thank goodness I know there are fantastic medical staff that mend and repair us so we can continue our lifestyle.

In addition to our friends, family and loved ones who help, advise and **care**, there are support organisations out there, so we are not alone.

I now know personally a little about prostate cancer but I don't know, why me!

My treatment is so far so good and a hormone needle in the bum is just a small part of my mending.

Not all cancers and not all of us are the same though.

Three words of advice from my research :-

Determination - Resilience - Patience

I was diagnosed early with Prostate Cancer following an annual full blood test and further scans/tests showed my PSA was through the roof.

The fantastic staff at Nepean Cancer Clinic have given me the best most suitable treatment I could ask for.

My lifestyle has not changed too much so I am the luckiest man in the world.

Thank you,

Paul (age 64)

WELCOME TO NEW P.C.F.A.CEO

We welcome Anne Savage to the position of Chief Executive Officer of PCFA. That doesn't mean we are losing Prof Jeff Dunn. He is taking on the role of PCFA's Chief of Mission and Head of Research. Jeff and Anne have worked together for over 15 years and both are passionate about supporting men with prostate cancer, continuing research, awareness and advocacy.

A message from the new CEO

Dear Support Group Leaders and Ambassadors,

I'm writing on behalf of the team here at PCFA to offer you our full support as the latest wave of Covid wreaks havoc in our health system.

If you or your family, friends, group members, and workmates are impacted by disruptions to prostate cancer services, please don't hesitate to call our Telenursing Team on 1800 22 00 99.

We'll be posting the attached graphic on social media tonight as a way of reminding people that we're here to provide support. Please feel free to share this with others if you'd like to.

We'll also publish Telenursing awareness messages on the website and within our Online Community, together with an article in our enewsletter, Blue Sky Horizons, which will be sent out tomorrow evening.

A number of you have reached out to us for information and advice on vaccinations and wearing masks at PCSG meetings. Thank you – we are tremendously grateful to be part of a community that cares deeply about protecting community health.

With different rules in place in each state, please do comply with the public health orders for your local area, erring on the side of caution. If you're uncertain about specific risk issues, please don't hesitate to email or call me directly, or reach out to a member of our team.

Our Prostate Cancer Specialist Nurses are part of a frontline system under tremendous pressure, but we stand united in making sure that men and families are not forgotten. While many of our PCSNs are providing extraordinary assistance to keep their base hospitals running, our Director of Nursing Sally Sara is working closely with her team to ensure we are there to care.

The Irish have a saying – Ar scáth a chéile a mhaireann na daoine – under the shelter of each other, people survive.

If you or your families need anything at all, please reach out.

Best wishes,
Anne

Anne Savage

Chief Executive Officer

Mobile 0417 709 869
Free Call 1800 22 00 99

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PROSTATE CANCER – A PATIENT GUIDE

Here is a link to a large (100 pages) comprehensive document on Prostate Cancer. It is produced by the American Prostate Cancer foundation

A comprehensive resource on diagnosis, treatment, side effects, and risk factors for patients and families with a history of prostate cancer.

About this guide There are no two ways about it: being diagnosed with cancer is hard, and it is life-changing. Despite increasing optimism about treatment, today’s cancer landscape can be challenging, as patients have access to an unprecedented amount of information. There are millions of cancer-related webpages, blogs, and videos available at your fingertips. But it’s important to acknowledge that this isn’t always a helpful thing. A cancer diagnosis can be disorienting, and for many, the overwhelming volume of information available can be more of a burden than an aid. This third edition of the guide focuses all of the most current and most accurate information available about contemporary prostate cancer research, treatment, and lifestyle factors into one consolidated resource. It is for any man who has been newly diagnosed, who is in treatment, or is concerned about a rising PSA. Beyond that, it’s for any loved one or caregiver who wants to cut through the noise and get directly to need-to-know information for prostate cancer patient navigation. Lastly, as we are beginning to recognize the genetic underpinnings of cancer, this guide is for any family member who might want to understand how shared genes affect their own short- and long-term risk factors—and when they should be screened.

<https://prostate-cancer-support-nb.us20.list-manage.com/track/click?u=2e7ec4ff84549768194c6ef5a&id=5b8d13e159&e=9041a09ce3>



A ‘shout out’ to ‘our’ Prostate Specialist Nurse, Liz.

Many of you may know that in addition to her ‘day job’ Liz is a committed and very active member of the Blaxland RFS.

Liz, and a crew from the Blaxland brigade recently spent a week in Lismore on flood relief assistance.

Congratulations Liz and many thanks to you and your crew mates for the dedicated support and assistance that you give to the community. THANK YOU!

2021 Christmas Party and 20th Birthday Celebrations

On the 20th of December 2021, we held our Christmas Party at the Emu Sports Club. (The “new” home for our monthly Group meetings.)

The club provided the catering for us and, because of other commitments later at the Club; the party was a lunch time get together.

We were also able to celebrate the 20th anniversary of the formation of the Group.

We welcomed a number of Special Guests. These were Gabrielle Moran who, along with her late husband Alan, was not only a founding member but also the driving force in the establishment of the Group. Other guests were Coralie Faye from the Cancer Wellness Centre and Jim Lloyd from PCFA.

During the day, Gabrielle and Group member, Brett Sowerby spoke of the early days of the Group.

We were also able to make donations to the Cancer Wellness Centre and the PCFA.

(You will notice the amount shown on the cheque to the PCFA that the amount has doubled. This was because we made the donation on a day when all donations were doubled by a corporate backer)



THE 3 PROCESSES OF SLEEP:

Our sleep is controlled by 3 processes. Understanding these processes can help us to understand where our sleep can go wrong and relate to the sleep tips provided below.

1. Sleep Homeostasis

In very simple terms, the longer we have been awake the higher the pressure for sleep is and the sleepier we feel. When we go to bed in the evening, we need our sleep pressure to be high to be able to fall asleep.

It's like a rubber band, you need stretch in the band (sleep pressure) for it to be able to snap back into place quickly (fall asleep within 30 min).

Things that can negatively impact our sleep pressure are napping and caffeine. That is why it is recommended that we don't nap for too long during the day (less than 30 min) and avoid napping and caffeine intake within 6 h of our normal bedtime.

2. Circadian Rhythms

The two main circadian rhythms that influence your sleep are those in body temperature and melatonin.

In the evening your body temperature decreases whilst melatonin secretion increases. This helps you to fall asleep and stay asleep. The opposite happens in the morning to help you wake up.

However, the timing of these changes will depend on whether you are an "early bird", "night owl" or somewhere in between.

"Night owls" are driven to stay up and sleep in later, whereas "early birds" are driven to go to bed and wake up earlier.

If you are a "night owl" or "early bird", you need to make sure your bed and wake times align with these drives.

3. Sleep Automaticity

Sleep is an automatic process. Unfortunately, you can't tell yourself to sleep and then fall asleep instantly. In fact, sleep works the opposite way, the more you think about it, the worse it can get. If you ask a good sleeper what they do to sleep well, it is likely that they will say "nothing"!

In that way, sleep is its own separate entity. You can't be as prescriptive with sleep as you can be with your training (e.g. do 3 sets of 10). For example, if you set yourself the target of getting 10 h of sleep, striving to achieve that will result in you sleeping worse.

TOP 3 SLEEP TIPS:

1. Consistent Wake Time

You're likely to start feeling sleepy (with no nap) 16 hours after you have woken up. If your wake time is consistent, then your bedtime will also become consistent.

2. Stop trying to 'produce' sleep

Sleep is a PASSIVE thing. Shift your attention to things you enjoy (e.g. reading, watching your favourite Netflix show, listening to music etc.); this will take your mind off sleep and will help you fall asleep faster.

A word of warning on sleep hygiene. Don't treat this like a 'To Do' list as it's not helpful to have to perform certain behaviours to be able to fall asleep. Instead treat it like a 'To Don't' list. Check that you're not doing anything that's going to potentially sabotage your sleep. If you are, aim to change that behaviour. If you're not, then move on and don't worry about it.

3. Resist the temptation to 'catch up' on sleep by taking a long nap

Your brain is clever, if you have a bad night's sleep, then it will automatically adjust the amount of time you spend in different sleep stages the following night to compensate.

If you have trouble sleeping at night, fight the urge to take a long (more than 30 min) daytime nap. This will reduce your sleep drive, which is the only thing that can 'produce' sleep.

The role of Stereotactic Body RadioTherapy (SBRT)

SBRT is a form of radiotherapy that is delivered at a higher radiation dose per day but over a shorter period of time, 4-6 sessions versus 20-45 sessions (conventional external beam radiation therapy). The radiation dose is precisely targeted to the area containing cancer in a small number of fractions (hypofractionation) thereby avoiding surrounding structures and reducing toxicity. In the initial session, a team of experts that include radiation oncologists, radiation therapists, and medical dosimetrists can plan with precision how the dose can be most accurately delivered. Sometimes three small metallic markers (fiducial) are inserted into the prostate so the team can track exactly where the prostate is, especially as it moves with normal breathing. A high-resolution CT scan (simulation scan) is done after the markers are placed which helps to formulate the final customised radiation plan. The image-guided radiotherapy (IGRT) is then delivered with an advanced linear accelerator. The CyberKnife is a robotic system that uses artificial intelligence to deliver precise doses of radiation with extreme accuracy in select circumstances.

Endorectal devices

These devices are used to control the movement of the prostate and the rectum, either by fixing the rectum or by separating it from the prostate, decreasing the exposure of the rectal wall to high radiation dosages. Some examples of these devices are the endorectal balloon, hydrogel spacer and rectal retractor.

Localised prostate cancer

SBRT has demonstrated a favourable disease control and safety profile in several studies for low risk and intermediate risk localised prostate cancer as a definitive primary treatment¹. It is a recommended treatment option in multiple Uro-Oncology guidelines (ASTRO/ASCO/AUA).

Metastatic prostate cancer

Patients who have less than five metastatic deposits (oligometastatic disease) may be amenable to SBRT. This treatment is also known as metastasis-directed therapy (MDT). The aim of SBRT in this clinical setting is not only to eradicate malignant secondary lesions, but also to prevent further metastatic development and delay subsequent treatment escalation. It may also delay the progression to a castrate-resistant state. It has been shown that the maximum efficacy in terms of biochemical progression free survival is obtained within the first 6 months after treatment. This oncological advantage is still maintained at 24 months for a significant proportion of patients. Studies are underway to assess whether in the future SBRT may be given alone but for now it usually given with systemic therapy (androgen deprivation therapy). The biological rationale behind MDT effect relates to the prevention of disseminated subcellular clones from metastatic sites to the rest of the body improving oncological outcomes, treatment-free survival and thereby creating a positive impact on quality of life. The benefits of MDTs can be higher than those of ADT, particularly in patients wishing to delay systemic treatments for quality of life or comorbid illness concerns. There may also be an economic benefit. Research in this area is ongoing.

Salvage therapy

In a meta-analysis by Valle et al. SBRT has been shown to be an effective management option for those who have disease recurrence after receiving radiation as the initial treatment for localised prostate cancer. It may also be used as a salvage therapy to the prostate bed for disease recurrence after a radical prostatectomy. Future trials should address the use of SBRT in different clinical scenarios providing more information about total treatment dose, fractionation, combination therapy with ADT and lymph node irradiation.

Penrith Relay for Life



After two years of cancellations because of you know what...

The Penrith Relay for Life is back on this year!

Where :- Penrith Paceway, Station Street Penrith

When:- Saturday April 30th – Sunday May 1st 2022

Our participation in the Relay is once again being co-ordinated by our hard working Promotions Officer, John Kemp (johnchriskemp@gmail.com.)

Please contact John to advise him if you intend attending

Here is the link to register for the event.

<https://www.cancercouncil.org.au/relayforlife/Events/IT0001365>



Upcoming Events

Lions Wellbeing Forum (Free Event)

Date:- Sunday, April 3rd 2022
Time:- 9.00am – 12.30pm (Morning Tea provided)
Venue:- Horneswood Room – Penrith R.S.L. Club

(Group Vice President Graeme Renshaw will be giving a talk on Prostate Cancer Support)
RSVP by March 30th 2022

<https://www.eventbrite.com/e/lions-wellbeing-forum-tickets-292227820277>



A couple more events – (details yet to be finalised so ‘pencil’ it in your diaries)

Shannon’s Sydney Classic Car Show

Saturday August 13th – Sunday August 14th 2022
Sydney Motorsport Park (Eastern Creek Raceway)

Bunnings BBQ

Either
Saturday August 27th at Bunnings North Penrith or.....,
Saturday September 3rd at Bunnings South Penrith – Yet to be finalised

A NEGATIVE PERSON SEES THE GLASS OF WATER HALF EMPTY. A POSITIVE PERSON SEES IT HALF FULL. A REALISTIC PERSON ADDS TWO SHOTS OF WHISKEY, TWO CUBES OF ICE, AND SAYS "CHEERS"

NOT TO BRAG OR ANYTHING BUT I CAN FORGET WHAT I'M DOING WHILE I'M DOING IT.

Contact Us

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PAYMENT OF Membership Fees. Members can pay their annual Group Membership Fees by direct deposit to our bank account. Our Westpac Account Name is 'Nepean / Blue Mountains Prostate Cancer Support Group'. BSB is 032-837 and the Account No. is 206701. Current Fees are \$10.00 P.A. per family. Don't forget to advise who you are in the Lodgement Reference i.e. "John Smith Fees 2021"



**Would you like to make a cash donation to our group?
 Do you know any Group or Organisation that would like to make a donation?
 We are a registered charitable organisation and all donations are fully tax deductible.
 All donations help us to support cancer and health related projects in our local area.
 If you are able to assist, contact our Treasurer, Graeme Renshaw.**

Board Members of the Nepean / Blue Mountains Prostate Cancer Support Group for 2021 are as follows:-

President :-	David Wilkinson	'phone 02 4739 1685
Vice President / Treasurer :-	Graeme Renshaw	'phone 04 1827 6422
Secretary :-	Wayne Singleton	'phone 04 1494 5263
Medical Advisor :-	Liz McKervey	
Librarian :-	Bob Wittrien	'phone 02 4751 5920
Newsletter Editor:-	Alan Howard	'phone 02 4739 3320
Publicity / Web Site Manager :-	Vacant	
Promotions Officer :-	John Kemp	'phone 02 4739 2852

The Nepean / Blue Mountains Prostate Support Group Inc. is grateful for the support of its members and various local groups. This enables us to produce this newsletter and cover other incidentals in the running of the group. The Below the Belt 'Zipper' logo (Page 1) is copyrighted to Ms. Caroline Redwood and is used with her kind permission

The views expressed in this newsletter are not necessarily the views of the Group.

The Group does not offer medical or other professional advice.

Articles presented in this or any other issues are presented only as a means of sharing information and opinions with members.

It is important that health professionals should be consulted before making any decisions about any treatments.

This newsletter has been compiled by Alan Howard from material culled or provided.

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Nepean / Blue Mountains Prostate Cancer Support Group Web Site 'www.prostatesupport.org.au