We are here

F O R Y O U

And, your Family

PROSTATE CANCER SUPPORT
City of Onkaparinga Group
South Australia

An affiliate Member of the Prostate Cancer Foundation of Australia,

www.pcsog.org

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Malcolm Ellis **Mark Milosevic** **John Shields**

OUR GOLDEN RULE: We do not give medical advice, your GP, your Urologist and Allied Health Professionals are the only people who are legally qualified to give you medical advice.

We do however give you our wholehearted support.

Thank you to Noarlunga Community Hospital for allowing us to use the Boardroom for our meetings.
Thanks also to our Sponsors: Southern Primary Health and to all who support us.

SEPTEMBER 2017 NEWSLETTER (No 150)
Your own local Newsletter
Our Editor John Shields accepts responsibility for the content of this newsletter.

SEPTEMBER 2017 MEETING REPORT

Present: 15

Apologies: 6

BUNNINGS BBQ:

Many thanks to Mark Milosevic and an enthusiastic team of family, friends and relations, our annual BBQ atBunnings Noarlunga Warehouse was another great success.
Each year at Bunnings, we rely on the help of so many people, and it is encouraging to see the good response that we get when we ask for your help.
Once again enough money was raised to keep our Support Group financially viable.
Thank you to all who help us to achieve this goal each year.

Details of income and expenditure for the BBQ were circulated at the September meeting.
It was also good to see that the rain held off, and having twice the amount of space to work in made the job of preparing and serving the food and drinks, so much easier.

Also we have been given the opportunity each month, to have both, an information table and collect donations for Prostate Cancer Research, Awareness and Support.
I have sent a letter of thanks to Bunnings Activity Organiser, Milena Welchman.

Our Guest Speaker tonight was Sophie Otto,
Prostate Cancer Nurse, Repatriation General Hospital.

The following website is one of Sophie's recommendations.
Log onto:- pcfa.org.au/askthe experts

Sophie spoke about this later on in her talk with us and I thought that it would be good to highlight the website where it is easy to find.

Sophie said that Urology is moving from the Repat' to the Outpatient Clinics, at Flinders and Noarlunga Hospitals on the 16th, 17th and 18th of October, and the Clinics would be open on the 23rd of October.

Once again, Members and visitors interacted well with Sophie as she spoke about various aspects of Prostate Cancer, the treatment options, side affects and any ongoing problems that might occur after any one of the many treatments that are now available.
Everyone is different, and there is no, one treatment fits all - so to speak.

There are 120,000 men across Australia, living with Prostate Cancer and there were 18,138 newly diagnosed in 2016. When a man is diagnosed the information is sent to a Data Base known as South Australian Prostate Cancer Clinical Outcomes Collaborative (SA-PCCOC) . This was established in 1998 under a NHRMRC Centres of Clinical Excellence Grant, and is an ongoing collaborative venture of the University of Adelaide, Flinders University of South Australia, The Queen Elizabeth (TQEH), The Royal Adelaide (RAH), and the Repatriation General Hospital (RGH).

We are encouraged to visit their website which provides more information for:

- **Researchers and healthcare professionals**
- **Collaborators**
- **Men and their families affected by prostate cancer**

What we measure
Outcomes
Who can apply to use our data
Current projects and collaborations specific to the University of Adelaide
Committees
Presentations & publications

Website: prostatehealth.org.au/contact-us - South Australian Prostate Cancer Clinical Collaborative.

Sophie then spoke about Prostate Cancer Specialist Nurses, and said that PCFA is trying to get more nurses around Australia.
She then went on to discuss support for men and their family during and after surgery.

Sally Sara has set up a nurse led clinic to check PSA and discuss side affects, also Physical and Psychological aspects, and where to send you if further treatment etc. is needed. ***

Sophie expanded on Continence Nurses, the use of Ultrasound to make sure that we are doing Pelvic Floor exercises correctly, once a Catheter comes out.
It can be up to 12 months before improvement, because everyone is different and an artificial Sphincter has worked really well for some men.

Some good discussion took place around incontinence – an enlarged prostate – stress incontinence – the urge to go – overflow – and this all requires a very big assessment.

We also need to make sure that our bowels are working OK, and that we are not getting constipated. Some of our members told of their own experiences when they needed to

have a colonoscopy. A procedure where a fibre optic camera examination of the large bowel and part of the small bowel is done. A flexible tube is passed through the anus. This provides a visual diagnosis and the type of treatment needed.
Perhaps there is bleeding from the rectum and the person will be referred to the appropriate doctors.
We were then told all about erectile dysfunction and given after treatment information, and reminded that everyone is different. The medications that some members have used are Cialis or Viagra. Erectile devices were also discussed along with Penile treatment, Penile Prosthesis, referral to a sex therapist and psychological support.

Sophies talk encouraged members to talk openly and frankly about their own situations and demonstrated the value of having an interactive presentation like we had tonight.

Malcolm thanked Sophie for her talk and we all agreed that it will be good to have Sophie come back and talk with us again, after the big move away from the Repat'

***** Sally Sara is a Clinical Practice Consultant – Prostate Cancer Specialist Nurse at Repatriation General Hospital Adelaide.**

It will be interesting to find out just what will be available for local men when a Urology Department is set up here in Noarlunga.

PROSTATE CANCER REPORT

The following reports have been recorded for information purposes only and have not orginated from, or reflect the views, of the PCFA or the Prostate cancer Support Group.

They were copied from a report on verywell.com/the-best-therapy-for-newly-diagnosed-prostate-cancer-4115359

What are the Basics of Prostate Cancer?

By Mathew Schmitz MD
Reviewed by a Board Certified Physician
Updated November 2016 and again on August 25, 2017.

Three key questions everyone must have answered about Prostate Cancer.

Prostate Cancer Basics.

Whether you, or someone you know has been recently diagnosed with prostate cancer or you are simply interested in learning more about this important disease, there are three prostate cancer basics you should know.

1. **What is the Prostate?**

The prostate is a small, walnut - sized gland that exists only in men.
It is situated below the bladder and just in front of the rectum in the lower pelvis.
The bladder acts as a storage area for urine. When the bladder is emptied, the urine tavels through a small tube called the urethra to the penis then out. The very beginning of the urethra as it leaves the bladder passes directly through the prostate. This fact accounts for why so many men with either prostate cancer or BPH (Benign Prostatic Hyperplasia) develop trouble urinating. As the prostate enlarges, the urethra is pinched off, leaving a smaller tube to carry the urine from the bladder to outside the body.

The prostate's primary function is to produce much of the fluid that makes up semen Semen acts to protect sperm as it makes it's way out of the body.

The prostate is present from before birth and grows in response to male hormones such as testosterone. Blocking the production or effects of these hormones is one of the primary treatment options for prostate cancer.

2. What Is Cancer?

Cancer is most simply explained as cells in a certain part of the body that have started to grow in an out - of - control and unregulated way.

The human body is made up of billions of tiny units called cells. These are the smallest structures in the body that can be considered to be living. They can only be seen under high - powered microscopes. Cells normally go through a cycle of growth, division and death. When this occurs in an orderly fashion, cells are created and die in roughly equal numbers.
They also normally stay confined to the area of the body in which they were meant to be.

Unfortunately, certain cells sometimes begin to multiply much faster than they die. When this happens, these abnormal calle squeeze out nearby normal cells. These abnormal cancerous cells can also spread outside of their original site in the body and spread to other ares. When cancer from one body site has spread to other areas of the body, the cancer can be said to have "metastasised". This is always an unfortunate occurance as cancer that has spread is much harder to treat in general.

A cancer is named after it's original site in the body. For example, prostate cancer, even if it were spread to the bones or the colon would still be called prostate cancer and not bone or colon cancer. This would more appropriately be called "prostate cancer with metastasis to the bone."

All types of cancer are different. For example, prostate cancer is very different from lung cancer. The two are caused by different factors, diagnosed in different ways and treated differently. Regardless of the type of cancer, the underlying problem is the unregulated and abnormal growth of the cells in that part of the body.

3. What Is Prostate Cancer?

Since cancer is the uncontrolled and abnormal growth of cells in a certain area of the body, prostate cancer is simply the uncontrolled and abnormal growth of cells in the prostate.
Some men have BPH (benign prostatic hyperplasia). This is often confused with prostate cancer. With BPH, prostate cells multiply faster than they should. This causes the prostate to enlarge and the patient to develop difficuly urinating. With prostate cancer, the cells not only multiply faster, but also behave abnormally by spreading ouside of the prostate if not caught in time. BPH is not cancer, but can show some of the same symptoms.
The prostate is made up of many different types of cells. The gland cells (these cells that actually work to produce the fluid that is released into the semen) are nearly always the cells that become cancerous. The technical medical term for cancer that arises from gland cells is adenocarcinoma.

Early detection, prompt diagnosis and effective treatment are the mainstays of good prostate cancer care.
Selecting the Best Therapy for Newly - Diagnosed Prostate Cancer
Reviewed by a Board Certified Physician.

Active Surveillance, Surgery, or Radiation? What the Studies Say.

Due to the absence of well – designed comparative studies, treatment selection for prostate cancer has been highly controversial. However, in October 2016, two landmark articles published in the New England Journal of Medicine reporting 10 year results from

1,643 bold volunteers who allowed themselves to be randomly allocated (akin to "drawing straws") to treatment with either surgery, radiation or active surveillance.

The first study campared 10 – year survival outcomes, while the second, companion study, used questionaires to compare the quality – of – life outcome. First, we will discuss the survival question. Then we will discuss the quality of life implications.

The Importance of Study Design
Finding volunteers to participate in a randomly allocated therapy, rather than choosing treatment themselves, is hard to accomplish. It's no surprise that this is the only study ever published of this type. Nevertheless, randomization is essential to ensure that patients in each of the three groups are equally healthy and have an equivalent type of prostate cancer. Without an assurance of parity between the groups, the study would be untrustworthy.

Comparing Yourself to the Study
The main value of a randomized study is that newly – diagnosed cancer patients can get accurate information about how the three most common treatment options compare. However, to make accurate comparisons, a patient's profile must be similar to the patient's who participated in the study, So, let's review the profile of the study participants. Their ages ranged from 50 to 69, with the average age being 62. The average PSA was 4.6. In one fourth of the men, the doctor could feel a nodule on the prostate with his finger.
Nine out of ten of the men had PSA levels less than ten (although there were a few patients with PSA levels between 10 and 20). Three-fourths of the men had Gleason 3 + 3 = 6, one – fifth had Gleason 7, and one - out of fifty of the men had Gleason scores of 8 to 10.

Monitoring With Active Surveillance
Monitoring anything called "cancer" sits poorly with patients and doctors alike. It is a fairly new idea and the methodology is still evolving. The monitoring method in this study relied almost exclusively on PSA. The use of follow up biopsies or imaging with multiparametric MRI was not recommended which is unusual by today's standards. Over the ten years of the study, almost half of the men in the surveillance group had surgery or radiation which is not unusual. The basic philosophy behind active surveillance is to watch men closely, and if the cancer grows, apply curative treatment before the cancer spreads.

The Impact of Treatment on Survival
The primary design of the study was to answer one question – *survival.*
When men first hear that they have cancer, most are consumed with thoughts about how to avoid early mortality. If survival is the priority, this study clearly reports that *treatment approach makes no difference*

In all three groups, the result was the same. Only one percent of the men (a total of 17 men) died from prostate cancer within the first ten years. This figure is even lower if we consider what the outcome would have been if the men with Gleason 7 and/ or a palpable nodule were excluded from the study. In the first 10 years, there were only six deaths in men with Gleason 6 and a normal rectal exam (the six men were equally distributed across the three groups). The impact of treatment on mortality, at least during the first ten years, appears irrelevent.

What About Metasases ?
This is not a super high priority question in men who are pushing 70; men in their 80's are more likely to die from unrelated causes. But It's certainly a relevant question for men who are in their 50's. The study does report a slightly higher risk of developing metastases for the group of men who were on surveillance compared to immediate surgery or radiation. Specifically only 29 men, 13 who had surgery and 16 who had rediation,

were living with metases after 10 years; whereas 33 men on surveillance had metastases. This calculates out to a 3 percet higher risk of metastases with surveillance compared to

immediate surgery or radiation. Not a very big difference, but certainly consequential if you are one of the unlucky men in the 3 percent.

The Impact of Metasases on Survival
Since at least 50 percent of men who develop metases will eventually die from prostate cancer, it appears, according to this study, that men who are treated with active surveillance will have a slightly higher mortality rate (perhaps 1 to 2 percent higher) that will occur 10 to 20 years after diagnosis, compared to the men who undergo immediate surgery or radiation. However, this fact should be taken with a major grain of salt, considering that the surveillance techniques were inadequte by modern standards.
As noted above, the men were only watched with PSA. They had no regular scanning with multiparametric MRI, nor were any screening random biopsies performed on a scheduled basis. These patients were left very much to fend for themselves. Considering this astonishing level of neglect, an increased metastases rate of only 3 percent actually seems rather low.

Surveillance Technology Has Dramatically Improved
There is another compelling reason to believe that the higher metases rate reported in this study *overestimates* the danger of doing active surveillance. The profile of the men who were admitted into this study is not typical of the type of men who are normally recommended for active surveillance. Over a fourth of the men in this study had a Gleason score of 7 or above, a palpable nodule detected on digital rectal examination of their prostate, or both. This is a much more aggressive type of cancer profile than is usually advised for monitoring.

Technological Improvements With Surgery or Radiation?
Before we leave our discussion of survival and move on to the discussion of quality of life, I have one further observation to offer. I criticized the stidies methodology by relying on PSA monitoring alone as inadequate. But what about the techniques for surgery or radiation? Would we expect a higher cure rate using 2016 technology compared to what men in this study received? The short answer is no. Although studies of robotic surgery report faster healing, the cure rates and the rates of sexual and urinary recovery have not improved. With regards to the external beam radiation, cure rates and side effects with modern IMRT are in the same range.

Quality of Life Matters if Survival is the Same
The pursuit of active surveillance only makes sense when interpreted through a quality of life perspective. The only reason to forgo curative treatment is the well founded concern that normal sexual and urinary function will be seriously impaired. If treatment had no side effects, everyone could have treatment; men could move on with their lives and forget about monitoring beyond a periodic PSA check. However, let's address the most common treatment – related problems, the risk of impotence and incontinence.

Questionairres Before and After Treatment
In the companion study evaluating quality of life, all participants were questioned about their sexual function and urinary control prior to treatment, 6 and 12 months after treatment, and annually thereafter. In this comparison, surgery was easily identified as the worst option from a quality of life standpoint. Prior to treatment, only 1 percent of men had urinary incontinence and needed absorbent pads. But that increased to 46 percent 6 months after surgery and slowly improved to 17 percent 6 years later. Six years after radiation on the other hand, only 4 percent of the men required a pad. Eight percent of the men on surveillance required a pad (remember that close to 50 percent men on active surveillance underwent delayed surgery or radiation).

The Impact of Treatment on Sexual Function

I think the most concise way to communicate the study findings on sexual function/impact is to provide you with a direct quote from the study.

"At a baseline, 67% of men reported erections firm enough for intercourse but by 6 months that fell to 52 % in the active-monitoring group, to 22% in the radiation group and to 12% in the surgery group. Erectile function remained worse in the surgery group at all time points, and although there was some recovery to 21% at 3 years, this rate declined again to 17% at 6 years. The rate at 6 years for the radiation group was 27%. The rate in the active monitoring group was 41% at 3 years and 30% at year 6."
While there will be an inevitable decline in sexual function over time in these relatively elderly men, results still show that surgery has a far bigger negative impact than either radiation or active surveillance. As pointed out in the study, a third of the men in this age group are already impotent prior to treatment. Since previously impotent men cannot be made more impotent with radiation, and other serious side effects were rare, there seems to be little motivation to avoid radiation in the subgroup of men who have preexisting impotence

Conclusions from These Two Landmark Studies.
First, survival rates with active surveillance are equal to immediate surgery or radiation out to 10 years. To ensure safety and survival rates beyond ten years men contemplating active surveillance should rule out the presence of any Gleason grade disease of 7 or above with a multiparametric MRI at baseline followed by annual scans. Second, survival rates with radiation are equivalent to surgery but with far fewer urinary and sexual side effects. Apart from it's sexual side effects, radiation is remarkably well-tolerated. If treatment is deemed necessary, radiation is a much better way to treat prostate cancer than with surgery.

Rito's:
Support Group members, their family and friends are invited to attend a luncheon, or have a cup of tea or coffee, and a friendly chat, at Rito's Cafe 101 Beach Road Christies Beach, on the third Thursday after each Support Group meeting.
This is proving to be a good opportunity to just relax and talk about life in general, and gives real meaning to that word "Support".

Newsletters received with thanks from:
Andrology Australia, Prostate Melbourne, Prostate Heidelberg, Sydney Adventist Hospital PCSG.

"NEXT MONTH WILL BE OUR FOURTEENTH BIRTHDAY"

OUR NEXT MEETING IS ON WEDNESDAY 4th OCTOBER 2017 AT 6.30 PM.
OUR GUEST SPEAKER IS UNABLE TO ATTEND
WE MAY HAVE A LOOK AT A PROSTATE CANCER WEBINAR

There is a lot of information about WEBINAR'S on the Internet.
See: What the heck is a WEBINAR?
+ very+ well + webinar
There is also a free book for anyone who wants to create great webinars

Info.workcast.com/webinar-best-practices?utm_campaign

https://youtu.be/6ou1t0dpwew?list=PLRyBYF-CJVsiRnKVzmXRs4ZH6dnWZGTzm

Right click - then left click on open Hyperlink – then click on a Video
The above lengthy printed reports are being phased out.