

PAYNEHAM PROSTATE CANCER SUPPORT AND AWARENESS GROUP NEWSLETTER

PROUDLY AFFILIATED
WITH THE PROSTATE
CANCER FOUNDATION
OF AUSTRALIA



MAILING
ADDRESS:-
PAYNEHAM
P.C.S.A. GROUP
1 BRIXHAM RD,
ST AGNES.
5097

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<http://www.pcagsa.org.au/pages/paynehampsag.html>

WISH TO REACH US BY EMAIL

PHIL DAVIS; classic100@bigpond.com

Supporting Quality of Life

For further
Information

PH; PHIL(08)
82632217.
PETER (08)
82635556.
ARTHUR (08)
82894180.

WELCOME TO THE MARCH 09 EDITION OF OUR NEWSLETTER.

The Payneham Prostate Cancer Support and Awareness Group has been formed to provide friendship support and information for people who have been affected or diagnosed with Prostate Cancer.

WE WOULD BE DELIGHTED TO WELCOME YOU ALONG TO OUR MONTHLY MEETINGS WHICH ARE CONDUCTED AT THE PAYNEHAM R.S.L. CLUBROOMS, 360 PAYNEHAM RD, PAYNEHAM. WIVE'S/PARTNERS OR OTHER FAMILY MEMBERS ARE ALSO VERY WELCOME.

Next meeting; Tuesday the 17th of March 2009, commencing 7p.m.

Speaker; General Discussion followed by an address by Paul Redman, who is the Support Group Service Manager, employed by the Prostate Cancer Foundation of Australia. He will speak in regard to his role and involvement with support groups and also an insight into the many activities of the Prostate Cancer Foundation of Aust.

REPORT FOR OUR FEBRUARY MEETING.

Chair person. Phil Davis,

Present 40

Apologies, Al Porter, Richard and Valerie Tula, Geof Fuller and Marilla Barnes.

A Big Welcome to our New Members to a Support Group; Harvey & Beryl Cheatle, Dean & Betty Conry, Doug & Kay Day, Michael & Maureen Donaghey, Garry & Alison Eckermann, Denis & Lorraine Koch, John & Robyne Marr, Klaus & Rosemary Maurer, David and Adrienne Radbone, Brian Scriven, John and Pam Scutter.

CHAIR PERSON'S REPORT;

It was a tremendous privilege to chair our first public meeting at the Payneham R.S.L. on Tuesday the 17th of February 2009. Although we were all perhaps a little nervous and curious at the commencement of the meeting, we all steadily got to know each other, relax and become more at ease. No matter how meticulous one was prior to our meeting everything did not progress without some pesky hiccups, however we will endeavour to remedy them at future meetings. When we have some new electronic equipment, including an over head projector it will allow us to re-locate the meeting into the auditorium at the southern end of the Payneham R.S.L. complex.

We were very fortunate indeed that quite a number of people who attended our first meeting were actually attending their first Prostate Cancer Support and Awareness Group meetings. They all contributed to the meeting in a positive and forthright manner which was greatly appreciated by all. I think we all gained as a result and I look forward to greeting all again at our next and future meetings

Being diagnosed with prostate cancer is a great leveller, we as a group can share our wisdom and support others and each other and also advance the interest in prostate cancer and contribute to improve the outcomes of all those affected. By attending a Prostate Cancer Support and Awareness Group, statistically we live longer and also people with strong social ties enjoy better health. As meetings progress a lot of information will be presented by a variety of speakers, which may answer many question and also there will be an exchange of information during discussions by others walking the same or similar path, this may assist in lightening the load and meeting the challenges as they arise. In my view we are all people of substance and wish to continue enjoying life, we still all have dreams.

PRESENTATION FOR THE EVENING.

Our speaker for the meeting was **Kevin O'Shaughnessy**, who not only exhibited a tremendous amount of empathy and understanding for men who have been diagnosed with Prostate Cancer but also their wives and families. Kevin who has not followed a typical path towards becoming a registered nurse, having been a hotelier for 10 years prior to nursing, is now continuing his studies at the University of S.A. by undertaking an Honours degree in Medical Science. As a part of that degree and being inspired for a variety of reasons which have impacted on him during his life he undertook to conduct research in what was titled;

“What themes emerge from the experiences of men, in the medium to long term phase following prostatectomy for prostate cancer?”

Firstly he conducted a Literature Search, followed by one on one interviews and focus group discussions which were recorded and involved participants who had all had a prostatectomy for prostate cancer.



LITERATURE SEARCH

Firstly it indicated that prostate cancer was the most commonly diagnosed cancer amongst males in Australia.

Some examples of themes which Kevin found in his literature search indicated men had the following concerns;

1. Fear of Cancer Recurrence.

The fear of the return of prostate cancer is a substantial burden for men, before and after treatment.

2. Sexual Health

Sexual health and the ability to engage in an intimate relationship is valued and an important part of the general health of most people, not only those who have had a prostatectomy. Erectile dysfunction is a dreaded complication following prostatectomy. The incidence of erectile dysfunctions following prostatectomy is unclear as there are few studies on sexual dysfunction in patients with prostate cancer. Some research suggests erectile dysfunction occur in 30% to 98% of men depending on the nerve bundles spared and the definition of dysfunction.

3. Incontinence

Post prostatectomy problems with continence are not just physical, but also psychosocial. The psychosocial factors associated with incontinence become more important to men as they resume their former lives. Resulting in disruption to their social lives and fears of leakage and incontinence were expressed in the literature review.

4. Body Image

Men who have had a prostatectomy may have an altered body image.

Body image can be described as a sense of a person's own body and a sense of what a person wants to look like.

5. Aging

Longer life expectancies and better surgical outcomes, ensures men who have a prostatectomy are likely to live with post operative complications and problems longer. Younger men's experiences may be different than men diagnosed later in life.

6. Regret

Regret of one's treatment choice emerged in the literature as an area of concern expressed by men who had been treated for prostate cancer. This has implications for men making decisions about their treatment.

7. Masculinity

Only men experience prostate cancer. Men interpret the world including their health differently than women. This has implications for researchers investigating men's experiences and for health care professionals caring for them. Men find it more difficult to discuss sensitive issues. There is scant research into the most appropriate method of eliciting frank and honest responses from men, especially when they are discussing topics they find embarrassing, or of a sexual nature.

8. Embarrassment was a recurring theme.

Men are embarrassed with incontinence, sexual dysfunction, changes to their bodies and talking about sensitive issues.

Kevin's Literature review concluded that men need to be fully informed about a prostatectomy and its likely biological, emotional, social and psychological impact.

Further research into the experiences of men who have already undergone a prostatectomy is needed and requires frank and honest feedback from men concerning their own experiences.

KEVIN'S RESEARCH INVOLVING MALE PARTICIPANTS;

This involved face to face interviews with individuals and focus groups, consisting of males who had all had a prostatectomy for prostate cancer.

KEVIN SUMMARIZED THE OUTCOME OF HIS RESEARCH UNDER THREE CATEGORIES;

- (a) Description of the interviews with an emphasis on the men's actual words and the non verbal interaction.
- (b) Themes already found in literature.
- (c) Unexpected results.

INTERVIEWEES EXPRESSED THE FOLLOWING CONCERNS.

1. Decision Making.

Quotes: "It was a pretty tough decision. It's the two things you really don't want to think about isn't it.

Like being impotent and being incontinent, it's like the two, but then again you don't want cancer either, kind of thing."

"I thought I want to get rid of this bloody cancer!"

2. Regret and Loss

Quote: "There is a sense of loss, when you been enjoying, enjoying sex for all your life, and then suddenly it's not there anymore."

3. Love

Quotes: "I am confident in how we have created our love, in the sexual side. It's quite good."

"I want to be a considerate partner."

4. Hope

Quotes: "I am one of those blokes, who if something goes bad, there is always something good comes out of it."

"The bad thing is kind of getting diagnosed, at fifty, but the good thing was kind of like, well you hope you can get over it, and may be have twenty years of life or thirty years of life left."

5. Fear

Fear of Death!

Quote; "Because my father passed away, when I was diagnosed, I thought I was going to die and that was it. It is a funny feeling. You think shit!! I am going to die."

Fear of Cancer Returning

Quote; "Now it is every six months again, a day or two before that test you have that feeling...(scared)...no matter how positive you are."

KEY THEMES

The literature review and this study indicated common themes and issues confronted by males who have had a prostatectomy.

Fear of cancer recurrence; Quality of life issues, Sexual Health Issues, Incontinence, Body image, Ageing; Regret;

UNEXPECTED RESULTS

The literature did not reflect these themes as being significant, but the men in the study did.

Isolation, Love, Hope, Faith, Fear, Health Literacy deficits, Coping skills of men not supported, Support Group's size was important.

The men interviewed identified needing help with; Pre-operative education, Decision making, Post operative education, Anxiety, Emotional and Relationship Support.

KEVIN CONCLUDED;

People who care for these men need research that reveals the experiences of men following prostatectomy.

Reading this research can engender empathy.

Empathy reduces the isolation men experience.

This study engenders empathy because it allows people to walk in the shoes of the men who were interviewed.

Further study into men's experience post prostatectomy and methods of supporting these men in the medium to long term is required.

Thank you Kevin.

On behalf of every one present at the meeting a very big thank you, for your excellent and very relevant presentation which related to each of us in some way. You exhibited genuine concern and care and we look forward to your continued interest and chatting with you at future meetings.

OUR LIVES DO MATTER

WE DO NOT GIVE MEDICAL ADVISE PLEASE TALK TO YOUR HEALTH PROFESSIONAL, WE ALSO DO NOT RECOMMEND TREATMENT MODALITIES, MEDICATION OR PHYSICIANS.

The Payneham R.S.L. is located on the southern side of Payneham Rd, about 100 metres east of the intersection of Payneham Rd and Portrush Rd. A car park is available on the eastern side of hall, enter eastern side door of RSL from car park.)

Membership to join the Payneham Prostate Cancer Support and Awareness Group is free as the group is funded in part by the Prostate Cancer Foundation of Australia, however we do welcome and depend on donation to fund the remainder of our expenses.

Supper (Tea Coffee and Biscuits) is provided free of charge at each meeting and the bar at the R.S.L. is open prior to and after each meeting.

Special Thank you to Arthur & Kathie Seager, Brian & Coralie Thomas, Peter & Jenny Woodrow, Barry & Margaret Oakley, Reg, Mark & Jan York-Simpkin for their assistance and also distributing Flyers

FUTURE MEETING

Tuesday 21st of April 2009

Our Guest Speaker will be Dr Graham Lyons, who will speak in regard to diet, anti-prostate cancer foods and also supplements.

For further information or a chat please call Phil Davis, Ph82632217, Peter Woodrow, 82635556 or Arthur Seager, Ph 82894180.

**A SPECIAL THANK YOU TO THE COMMITTEE OF THE PAYNEHAM
R.S.L.**
