



Proudly Affiliated
With the Prostate
Cancer Foundation of
Australia

Payneham

PROSTATE CANCER SUPPORT AND AWARENESS GROUP

NEWSLETTER

Mailing Address

Payneham P.C.S.A.

1 Brixham Rd

St Agnes. 5097

August 2009

Vol 1 No 7

Website www.psapayneham.org

Wish to reach us by Email

Phil Davis classic100@bigpond.com

For further Information
Ph Phil (08) 82632217 or
Peter (08) 82635556 or
Arthur (08) 82894180.

**Next Meeting 7p.m.
Tues 18th August 2009
Payneham R.S.L.,
360 Payneham Rd,
Payneham**

WE WOULD BE DELIGHTED TO WELCOME YOU ALONG TO OUR MONTHLY MEETINGS, WIVES/PARTNERS OR OTHER FAMILY MEMBERS ARE ALSO VERY WELCOME. (Prostate Cancer also affects wives/partners and family.)

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

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

REPORT FOR OUR JULY MEETING

Chair person Phil Davis.

Present 36.

Apologies; Brian and Coralie Thomas, Harvey and Beryl Cheatle. Brian Scriven, Robyn Davis, Ian Milroy, Peter O'Connor, Ken Prime, Al Portman and Pam Scutter

Welcome to our New Members;

Ivan Wooller, George and Agnes Cairns.

GUEST SPEAKER

DR SAMANTHA PILLAY, UROLOGIST

WILL SPEAK ABOUT THE
WIDE SPREAD PROBLEM OF
URINARY INCONTINENCE

CHAIR PERSON REPORT

Unfortunately our programmed speaker for the evening Mr Jehan Titus, a Urologist who had intended to speak to us in regard to erectile dysfunction and men's sexual health, was unable to attend our meeting due to illness. He forwarded his apologies and one hopes he has now fully recovered and will be able to speak to us at a future meeting.

In an attempt to provide some insight into the issue of erectile dysfunction, I have included the very positive story of Jo-Anne and Jerry Hardy. (Page 3) It is written by Jo-Anne in regard to their journey with prostate cancer and how they coped with and overcame erectile issues. It is an insightful and inspiring story, free of vanity, which I hope you enjoy. They are an American couple, from Michigan; the article is reprinted courtesy of the Us TOO Chapter Newsletter. Us TOO is a similar organization in the U.S.A. as the Prostate Cancer Foundation is to us in Australia.

During our July meeting, Peter Woodrow advised us, how he and his wife Jenny enjoyed attending a prostate cancer support and awareness meeting at Tweeds Head, whilst they were on holiday in Queensland. He mentioned they were a very welcoming group of men, but unfortunately Jenny was the only woman in attendance. (I think she enjoyed the extra attention) Women are welcome to attend their meetings, but on the occasion of their visit, none were in attendance. Peter and Jenny enjoyed the meeting and noted how similar it was to our meetings, the group also produces a newsletter. The group in general placed great importance on ensuring the message concerning regular PSA tests was emphasised to our next generation.

TREASURER'S REPORT

During the evening our Treasurer Arthur Seager spoke about recently commencing hormone therapy and the now amusing aspect of what he initially thought were side effects, but in fact was a minor but unpleasant bout of gastro and unrelated to the androgen deprivation therapy.

Arthur also spoke of his very rigid diet that he has adhered to for the last four years, including some supplements he has in his endeavour to prevent and or slow the progression of his prostate cancer. There will be more on this in our next newsletter including a list of food and supplements and where he obtains them from.

FUTURE MEETINGS

For the remainder of this year we have some excellent speakers who will address some very relevant issues which many men suffer after treatment.

TUESDAY SEPT 15TH 7P.M.

ROSALIE DONHARDT, INCONTINENCE NURSE,
GOOD BLADDER & BOWEL.

DR RIEGER, COLORECTAL SURGEON,
BOWEL.

TUESDAY OCT 20TH 7P.M.

DISCUSSION EVENING. FACILITATED BY
KEVIN O'SHAUGHNESSY.

TUESDAY NOV 17TH 7P.M.

ANNUAL GENERAL MEETING.

ELECTION OF OFFICE BEARERS FOR 2010,

SOCIAL EVENING AND BARBECUE.

Reclaiming Intimacy – One Couple’s Journey

By Jo-Ann Hardy

(Jo-Anne and her husband Jerry are members of a Michigan Prostate Cancer Support Group.)

Diagnosis

In 2000, my husband, Jerry, was 46 years old and I was 43. We were about to celebrate our 24th wedding anniversary and life for us was good. Our daughter was a sophomore in college and we were greatly enjoying our empty nest.

Jerry had a few complaints of a slight urinary problem, which we thought was an infection. The doctor ordered a PSA test as part of his discovery process, having already established a baseline PSA the year before, of 2. During this particular visit, Jerry’s PSA was only a relatively low 4.5, but before we knew it we found ourselves sitting in a urologist office facing a prostate cancer diagnosis. There was no family history for him, so it was quite surprising. Jerry’s 47th birthday gift was a clean bone scan.



Seeking Options

After the initial shock, we began to research all of the treatment options and to “doctor shop”. While reviewing anticipated outcomes, we also looked at all of the side effects of each possible treatment, one of which was erectile dysfunction, which was associated with

several treatments.

Ultimately, we chose an option we thought provided the best chance of long term survival.

Once the doctor and hospital were chosen, plans were made for a radical prostatectomy. I cannot emphasize how important the concept of “doctor shopping” or “interview is”. As patients and caregivers, we are our best and most passionate advocates! It is so important to find a physician

that is not only highly skilled and educated, but also, one that related to you in a manner that is comfortable for you.

A New Challenge

Once Jerry recovered and went back to work, we started to be more concerned about sexual intimacy. The nerve sparing procedure left Jerry with feeling and sensations, but only a partial erection. One of our favorite urologists’s described it like this. An erection is like a three legged stool, you have to have all three legs for it to work. Is it firm enough, does it last long enough, can you get it when

you want it. If one of the three elements does not work consistently, then you might want to seek the advice of your doctor, and so we did.

We tried oral medication first (Viagra and Cialis) and then the caverjet injections which did not work for us. Most urologists who specialize in ED recommend that the patient move along the continuum starting with the least invasive modalities of treatment to see if they are successful before giving thought to surgical intervention, which is not reversible.

We kept the lines of communication open and talked a lot about it, but it really was a sad time for us. At the same time, let's be clear: we weren't just twiddling our thumbs as we searched for answers. For us, the inability to have intercourse was not the same as the inability to be sexually intimate. We found plenty of fun things to do along the way.

Our Choice

After the radical prostatectomy, we allowed enough time for all of the nerves to heal but, after waiting 3 years for Jerry's erections to return, we decided to have a penile implant. Many urologist suggest that if an erection has not returned by the end of the first year after treatment, that most likely, it will not.

We realize that all couples have to find their own comfort level, but for us, the ability to have intercourse was extremely important. We wanted to see if this was a way that we could restore that special part of our relationship.

As we talk to many patients, so often, there is a resignation that there are no solutions and that maybe the ability to have intercourse was never important anyway. This really saddens me, because sometimes patients and partners give up. Maybe it's embarrassment,

or old messages that replay in their heads, frustration, or difficulty in communicating that keep them from seeking other answers. For other couples, it really is ok and they have found other ways to express their intimacy that are satisfying for them both. But, for us, after trying and researching our options and some more doctor-shopping, Jerry had a penile implant.

The Outcome

Usually patients who receive a penile implant come home from the hospital the same day as the procedure. It is generally referred to as a 23 hour surgery and in our case, Jerry did stay overnight. As far as recovery, after swelling from the surgery goes down, it is far easier to have a better outlook on the reason you had the surgery. Warm baths 3 times a day were definitely a highlight.

The surgery was successful and once again, we have reclaimed a satisfying level of intimacy. It was a long journey but well worth it.

What we learnt along the way.

- 1. It is possible to reclaim intimacy after prostate cancer treatment.**
- 2. Letting go of embarrassment and start talking. Have frank discussions with each other and your doctor or change doctors, if you need to.**
- 3. Be willing to explore options and be committed to finding a solution.**
- 4. Become educated about the options.**
- 5. Have hope.**

PROSTATE SUPPORTER NEWSLETTER EDITOR

David Sly

Strange as it may seem, the editor of the Prostate Supporter newsletter is not affected by prostate cancer and has no personal cancer journey to speak of – yet such impartiality has allowed journalist David Sly to give the Prostate Supporter monthly newsletter a sharp, incisive edge that helps make it a valuable document to all readers.

“The newsletter’s many contributors from prostate cancer support groups throughout South Australia and the Northern Territory all have important personal information to impart – they don’t need an editor’s endorsement or agreement, but they often need a writer’s pen and an editor’s eye to make their story clear and concise, and this is where his professional skills and training are of benefit.”

David came to this role as a professional freelance journalist with almost 30 years’ experience, having previously worked as a feature writer, senior sub-editor and Food & Wine editor at The Advertiser Newspaper, as editor in chief of The Adelaide Review newspaper, as production editor at The Independent Weekly newspaper and with stints at The Herald Sun in Melbourne, and The News in Adelaide.

Editing the Prostate Supporter newsletter is part of a very diverse work portfolio that he currently undertakes, from being Food & Wine editor and senior feature contributor to SA Life Magazine, to writing contributions for more than a dozen national magazines and newspapers on food, wine, travel, snow skiing, business and profile interviews.

He also wrote the 240-page hard cover book *This Is, South Australia*, for SA Life Publications, and lectures at the University of Adelaide in food and wine writing (David was among the inaugural graduates of the Masters of Gastronomy course run by the university with Le Cordon Bleu).

“In essence, my task is to be a storyteller,” says David. “I strive to understand the core elements of a person’s story and help retell that with fairness, accuracy and a dash of flair, so that many others will understand and appreciate it.

“I obviously come to this newsletter as an outsider – engaged by Foster Hill Public Relations on the strength of my experience and diversity as a professional writer and editor – though I trust that my curiosity and concern about prostate cancer will reflect the interests of the average reader. Therefore I try to break down any jargon that only insiders can understand, to help make every item accessible. I believe one of the crucial ambitions of Prostate Supporter is to have its contents read by more people –not just as an information source for support group members but also as a promotional tool to help spread awareness about prostate cancer to those who remain uninformed. “

“While I have no direct experience with prostate cancer, I have great sympathy with cancer sufferers, as many of my dearest friends have been taken by different forms of cancer in recent years, and several more continue their struggles. I also had my niece Belinda suffer from leukaemia in her childhood – a wretched disease that she and her parents fought bravely against and won (Belinda is now 26, married, and working as a solicitor in Oxford, England).

Her plight made him an ardent supporter of childhood cancer charities, this year he took part in a major childhood cancer fundraising walk for the 'McGuinness McDermott Foundation,' trekking along sections of the Great Wall of China in June. It was a significant challenge for David, not only to raise funds for the charity, but also getting himself fit enough to undertake more than 110,000 vertical steps along nine separate stages of the Great Wall for six consecutive days. He found it an incredible experience and along with 15 colleagues endured everything from sheet rain, gasping humidity and blast furnace heat, which of course had to come on the day of his longest march, stomping about 17km from one township to another, covering 52 towers in between. You can get the gist of this day from the accompanying picture, with walking buddy Dan Haller at right and wild China sprawled out behind us.



“On top of those mountain peaks, the walking group shared profound moments, long silences and some tears as we remembered precious people taken by cancer. In the stillness of such an awesome panorama, it reaffirmed just how precious life is.”

I think all who read the 'Prostate Supporter Newsletter,' recognize and appreciate the abundant writing and editing skills of David.

[The Wesley Centre for Hyperbaric Medicine. \(Wesley Hospital Brisbane Queensland\).](#)

Hyperbaric Oxygen Therapy has positive outcome for people suffering with radiation proctitis.

A number of men who undergo radiation treatment for prostate cancer, whether external beam radiotherapy or brachytherapy or external beam in conjunction with high-dose brachytherapy will have long-term bowel and/or bladder problems caused by blood vessels in the irradiated field beginning to progressively scleroses which in turn reduces the blood supply to the point where it will not support tissue healing. These results in soft tissue radiation necrosis often referred to as proctitis. In the bladder it can result in bleeding (seen as blood in the urine) and painful and frequent urination and in the bowel it can cause excessive flatulence, frequent bowel mucus which, combined with excessive flatulence, can make life rather unpleasant. Symptoms can occur months, or occasionally years after radiotherapy.

There are surgical remedies which may rectify these problems, either completely or partially, but hyperbaric oxygen therapy (HBO) offers a non-invasive form of treatment where the sclerosed blood vessels are rejuvenated by a process called angiogenesis and tissue healing takes place. A recent published study looked at HBO treatment for radiation proctitis in the large bowel following radiotherapy for cancers in the lower abdominal and pelvic regions. Data on 120 patients entered into the trial indicated excellent results at the 2 year follow-up. A number of men attending Queensland Prostate Cancer Support Group meetings reported good outcomes following the treatment. Currently a trial is underway to evaluate HBO for bladder problems following radiotherapy.

Surgery Improves Survival Rate In Younger Prostate Cancer Patients.

Researchers at Henry Ford Hospital suggest men with prostate cancer under the age of 50 who undergo a radical prostatectomy will increase their chances for long-term survival, according to their recent study of 8,200 men. Often called an “old man’s disease” prostate cancer continues to affect men under 50. In fact, one in 10,000 men under the age of 40 will be diagnosed with prostate cancer this year.

To determine which treatment option offers the best chance for long-term survival for younger cancer patients, researchers studied more than 8,200 men under 50 with prostate cancer undergoing three types of treatment, active surveillance, radical retro-pubic prostatectomy and external beam radiotherapy. The cancer-specific survival in the active surveillance group was 78 percent at 16 years; in the radiation group it was 63 percent at 17 years; and survival was 94 percent at 21 years for those who underwent a radical prostatectomy.

“When given the choice between surgery, watchful waiting or external beam radiotherapy, patients younger than 50 with moderately to poorly differentiated prostate cancers have better long-term overall and cancer-specific survival when they opt for surgery”, said study author Naveen Pokala M.D., a urologist with Henry Ford Hospital.

(Henry Ford Hospital 11May09)

Library News Librarian Kathie Seager advises our Library is steadily growing, and books are available for loan at each meeting.

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 the hall, enter the eastern side door of the R.S.L. from the 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.

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.**
