

PROSTATE CANCER ACTION GROUP (S.A.) INC.

Affiliated with
Prostate Cancer Foundation of Australia



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NEWSLETTER

The views expressed in this newsletter are not necessarily those of the Group. This Group does not offer medical or other professional advice. Articles printed in this newsletter are presented only as a means of sharing information and opinions with members, with the object of promoting stimulation for independent thought and analysis, and sharing the experiences of others. It is not intended to recommend any particular treatment or product in this publication. Each person should assess the relevance to him/her self, and any person acting on information in this newsletter takes the responsibility for any such action. It is important that any person should consult with his/her health professional before making any decision about treatments, and all articles should be read in this context.

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FEBRUARY 2004 KILLING ME SOFTLY

This was the heading chosen by the "Weekend Australian" of Dec. 20-21 2003, for a full page story about prostate cancer (worth reading by all members). The article featured the case of a Geoffrey Moss, aged 48 when diagnosed with the disease in 1996.

Moss had a radical prostatectomy, and suffered more than his fair share of setbacks. Doctors discovered an aggressive cancer which had already spread outside the prostate gland. The surgery and other treatments, left him impotent and he suffered from severe incontinence. In addition to the surgery, he has had radiation (he considers that was botched), an orchidectomy, hormone therapy, and is currently undergoing chemotherapy for metastatic disease in his pelvis and lower back.

As a result of the emotional trauma, numerous procedures (many failed) requiring hospitalization, debilitating side-effects from the various treatments and lack of appropriate information and counselling, Moss has lost his wife (he had just married for the second time) and his job, and has had to sell two houses. He now resides in a caravan park, and is resigned to the fact that he has about a year to live. All this because people who should know better have not made a conscious effort to inform men about this disease.

While this case could not be regarded as a typical case, it demonstrates that a number of consequences can result from a diagnosis of prostate cancer. Even more, it demonstrates the lack of compassion and concern shown by those in high places who insist that PSA testing is not recommended, and who also insist that it is an old man's disease. I do not believe that any man of 48 would, or could, be regarded as "old". Apparently, such cases are regarded as a simple "blip" in any considerations about prostate cancer.

Moss is angry that he was not provided with information on treatment options following surgery. He was not even aware that his family history made him a prime target for the disease. He has every right to be angry, as have the numerous other men who have had a late diagnosis, due mainly to the air of ignorance about prostate cancer that is encouraged in Australia.

The publication of this article drew the inevitable comment from the CEO of Cancer Council Australia, Professor Alan Coates, who responded with his usual statement about men suffering in vain. I would like to know how Coates sees the suffering of Mr. Moss. Does he see the suffering of men diagnosed too late for meaningful treatment as being par for the course? Just one of those "blips", maybe? I believe that Coates has much to answer for in cases like this, and for the many men who live with the uncertainties associated with metastatic prostate cancer – most of whom were denied the opportunity of a potential cure because they were not informed of the disease, in a very similar manner to Moss.

An early PSA Test does, at least allow a man to monitor any indication of potential trouble with prostate cancer, and allow him to make informed decisions before it is too late to treat the disease. And I should know, because I had the great misfortune to attend a G.P. who followed Professor Coates' dictum to the letter. As a result, I had a PSA reading of 26 at diagnosis, and lost the opportunity to treat the disease effectively.

In his predictable response to this article, Coates seized upon the graphic description of the side-effects suffered by Moss as an illustration of the potential side-effects that may be suffered by any man who has been treated for a cancer that may not have been life-threatening.. He did not mention that this man was probably enduring such traumatic side-effects because he was not diagnosed before the cancer had reached such an advanced stage.. He also did not mention that modern treatment techniques continue to improve, and that the risks of such severe side-effects are diminishing, although not being totally eliminated. Surely recent advances in treatments must be weakening the threat of all those side-effects so vividly described, ad nauseum, by Professor Coates..

Nobody can tell us, exactly, whether, or not, individual cases of prostate cancer may be life -threatening. Nobody can tell us effectively that we may be undergoing unnecessary treatments. I am sure that most men, given the chance, would not willingly undergo any unnecessary medical treatment.

In cases like that of Moss, and many more that most support groups could name, when metastatic disease has become established, Coates appears to pretend that it does not happen. In his response, he stated that he “does not downplay the burden of disease and death caused by prostate cancer”. Of course not, he just avoids any mention of that in his crusade of perpetuating ignorance. In other words “Trust me, I am from the Government, and I’m here to help you. If you do get prostate cancer, don’t tell me”. There does appear to be a distinct wish to avoid any admission that some men could surely have been cured, if they had been aware of the risk of the disease, and had appropriate information available to them.

Sure, information Is available. But how are men to know about this when the wall of silence is being maintained at Cancer Council Australia level? What about those men living in rural and remote areas? They don’t have the same opportunity and access as do men living much closer to the cities. It is time that reliable, unbiased information and awareness programmes were made available to men, much as in the manner of breast cancer programmes for women. Note that I do not advocate for mass population screening, but merely a sensible programme to help each individual man make his own decision, based on unbiased factual and practical information. This is the least that we could expect in this age where there are so many aids available to communicate effective health programmes to men. In many, many cases, partners, too, want to be involved in such a decision. At present, even the partners of men at risk are being denied the opportunity to learn more about the risks of this disease. I doubt that many partners really look forward to becoming the carer for a prostate cancer patient. If Professor Coates does not want to undergo a PSA test, that is no reason for withholding information and awareness from all other men.

In following the discussion after the publication of the initial article, there were both optimistic and negative prospects for Australian men.

Coincidentally (?), on the same day as the publication of the Coates response, the Vice President of Cancer Council Australia, Ms. Judith Roberts also responded. Ms. Roberts will be remembered as being the Immediate Past President of CCSA, who resigned so that she could devote more time to preparing for succession to the position of President of CCA

In my 5-year association with this disease, I cannot recall ever having heard any public statements about prostate cancer being made by Ms. Roberts. (I stress that I have not heard any statements). However, as she now aspires to a higher position in TCCA, it would appear that it is incumbent upon her to take a more public stance on the matter. After all, it would not be appropriate if she were to deviate from the opinion of her CEO, would it?

This letter was critical of any comparison between the screening of women for breast cancer and any advocacy for screening for prostate cancer. If men thought that there was even the slightest chance of any variation to current policy, then think again. There will be no change, statistical outcomes will continue to take precedence over clinical outcomes, and many men will die unnecessarily from this disease because of lack of information and awareness.

The debate continued through the “letters to the editor” column, over several days, and it was gratifying to see some balance restored. Many of those letters and opinions were from personal experience. One comment from an ACT doctor stated; “As a urologist, however, the most tragic patients I have to deal with are those men who present with metastatic cancer who were never given the opportunity to make this choice because their doctor didn’t do a PSA test until it was too late.” He didn’t have to tell us that, but some people in high places find it convenient to overlook this aspect. (What, no statistics?)

However, the last word published was from Professor Tony Costello, and what a good retort it was. Here is somebody who really knows what the situation is – someone who is working at the “coalface”, someone who really knows what is happening in the real world. I hope to copy it into the “hard copy” edition of this newsletter – it really is worth reading, and puts a very good case.

The subject was probably well summed up in “The Australian” editorial of 23/12/03 – “.... that does not mean that it is better for men to remain ignorant about whether they already have the condition that will one day kill them. With the right information and

support, they will make the right choices. For far too long, and at the cost of far too many lives, this has been the cancer that dared not speak its name.” **HEAR. HEAR.**

It is high time that people like Coates and Roberts, et al came down from the controlled atmosphere of their ivory towers, and had a good look at this disease with the men who have been diagnosed. The true test of their courage would be for them to talk to the families of those men who have had to endure the trials of advanced cancer, and who have died unnecessarily because the general population is being kept ignorant about this disease. Talk to real human beings, not computerized statistics. Listen to the doctors who are working in the field. They cannot continue to ignore what really is happening to Australian men.

In the meantime we should acknowledge the courage and enterprise of “The Australian” for continuing to raise this topic in the public forum. They deserve our support for this. Long may they continue to keep the dialogue going, until a result is achieved that means that Australian men have the knowledge at their disposal that enables them to make their own informed decision about how they wish to monitor their prostate health, and no longer have to accept the paternalistic platitudes distributed by TCCA personnel.

AWARENESS MEETING AT SALISBURY **WILL THERE BE ANOTHER SUPPORT GROUP?**

It seems a long time ago, now, but the awareness meeting held in Salisbury, on November 18th was considered to be a successful function, despite not being able to draw our usual number of attendees. 45 people attended the meeting, which, according to Chris Duff-Tyler from Northern Metropolitan Community Health Service, is very good for this type of meeting in that area. The fact that our meetings continue to draw good attendances in all areas must surely be an indication that there is a need for a better awareness of prostate cancer.

Dr. Agnelo DeSousa addressed the meeting, as he has his practice in this area. His address was, again, informative, with a touch of humour, and was well-received by the audience. Some after-meeting comments also supported comments that we have received at other meetings addressed by Dr. DeSousa. Unfortunately, we have not been able to publish an analysis of the meeting response forms. The forms were taken by Ray Power for processing, but he was called to New Zealand on a family matter shortly after the meeting, and it is not known when he will return.

Subsequent to that meeting, Jeff, Theban, Coralie and I attended a meeting at Salisbury Downs, which had been organized by Chris Duff-Tyler. This was as a result of our awareness meeting, as he is very keen to establish a prostate cancer support group in the area, and has made it one of his aims for 2004. This meeting was attended by 5 men and two partners plus a representative from SHINE SA, and was addressed by Jeff, who spoke about the role of support groups and the PCFA.

The consensus of the small group was that efforts should continue with the aim of forming a support group in the area. Some of those present have been attending another support group. All appeared to be enthusiastic, and they have decided that the group should meet on the first Monday of the month, from 7.00pm to 9.00pm. It is to be hoped that all of these people will maintain their enthusiasm, and support Chris in his drive to achieve an active support group. There will need to be some hard work undertaken to spread the word.

GRANT NEWS

We have been successful with an application to the City of Charles Sturt, and the amount of \$500.00 has been approved from their Community Benefit Grant Program. This will allow us to conduct an Awareness Meeting in their area, and, hopefully, attempt to form a prostate cancer support group in the western suburbs. Their offer has been accepted, naturally, and we await receipt of their cheque.

This will allow us to then proceed with arrangements concerning venue, date and presenters, etc.

In the meantime, Secretary Jeff has been working hard to convince the Department of Premier and Cabinet that the Port Augusta presentation should be included within their previous grant, and grant us an extension of time to complete another rural presentation. Good news! They have perused our report on costs, and have rejected some of the expenses that we included. But, they have allowed us extra time to expend the full grant, including the amount that they rejected from other presentations. This means that we will be able to complete 3 presentations financed through that grant – Port Augusta, Barossa Valley, and one other, most likely Berri.

MAN ALIVE!

We are led to believe that everything is proceeding smoothly with arrangements for this event. Rather than type out all current information, I have attached copies of material from the organizers to the hard copy of this newsletter. I note that the event has

been listed in the official guide to the Adelaide Fringe 2004 (p.38). We can now make some more definite plans for our stall at this event, most of which should be completed at tonight's meeting.

The festival will celebrate men, their diversity and their contributions to families and community. Food, entertainment and variety stalls from many different cultures and community groups together with fun activities and games will create a lively and engaging event for families and individuals of all ages to celebrate men in the community. (Come and try thong-flinging)

CANCER LINK TO AGENT ORANGE

A study has found an increased risk of prostate cancer and melanoma among US Air Force veterans of the Vietnam War who sprayed the chemical defoliant Agent Orange, the Air Force says.

The cancer incidence was found to be 1.46 to 2.33 times higher than among the national population. An analysis of the study is to be published in next month's edition of "The Journal of Occupational and Environmental Medicine".

The Air Force released a synopsis of the article written by members of an Air Force group that has been studying the Agent Orange matter for more than 20 years.

An Air Force spokeswoman said it did not plan to release the study or the article before the edition was published. (From "The Advertiser" 24/1/04, p58)

Could be many Vietnam Vets in Australia who would be interested in this one. Question is: will this report be published in Australia? Could be worth watching out for the full report.

Green tea may protect against prostate cancer

Prostate cancer is usually diagnosed at advanced stage in China. In vitro and in vivo studies have suggested a protective effect of green tea, and epidemiological studies show that tea drinking is inversely related to oesophagus, lung, colon, breast, pancreas, stomach and skin cancers.

Men over 45 years of age with prostate cancer were found from in-patient records between July 2001 and June 2002. Men with prostate cancer (n=133) and controls who had no diagnosed malignant disease (n=274) were interviewed. A structured questionnaire measured whether the men were ever or never tea drinkers, and details determined from the ever drinkers.

In the prostate cancer patients 55% were tea drinkers compared to 80% of controls. Results showed that the controls had significantly more years of tea drinking, kilograms of tea consumed per year, tea leaves used per batch and the number of cups of tea per day. There was no difference in the types of tea or the new batches brewed each day.

The authors note that tea drinking could be a marker for other unknown dietary factors but that the active constituent of tea, epigallocatechin gallate, inhibits carcinogenesis in laboratory cell and animals studies. The authors discuss possible confounding factors in the study and conclude "increasing frequency, duration and quantity of green tea can lead to a lower risk of adenocarcinoma of the prostate". (IJC, vol108, pp130-135 - forwarded by Wendy Riordan)

OUR MEMBERS. Many thanks to Jack Dorrestyn for designing and printing our name-tags. They really look the part.

Our thoughts go out to Helen and Ray Power at this difficult time. Helen's father, in New Zealand, has kidney failure and is now in palliative care. It is not known when they are likely to return home to West Lakes.

SUPPLIES OF OUR NEW PAMPHLET ARE NOW AVAILABLE

ANNUAL PROSTATE CANCER CALL-IN WILL BE CONDUCTED ON 23rd SEPTEMBER 2004 – MARK YOUR DIARIES

Trevor Hunt