14th March 2005

The Secretary
Senate Community Affairs Reference Committee
Suite S1 59
Parliament House
Canberra ACT 2600

Dear Sir/Madam,

Re: Inquiry into services and treatment options for persons with cancer.

I became aware of the Inquiry and its request for submissions in one of our local newspapers.

I am a 71 year old male who has undergone a radical proctectomy for prostate cancer in November 2000. In October 2004 I commenced external beam radiotherapy for an increasing Prostate Specific Antigen (PSA). On Christmas Eve 2004 I completed my radiation treatment.

Following surgery I experienced the complications of incontinence and impotence. Following radiation I experienced the complications of bowel problems. As of this date I am still experiencing complications from both treatments. In both cases I was informed by my specialist that I would/could experience side effects following treatment.

My Urologist informed my wife and I that about 5% of his patients experienced incontinence and impotence. We thought they were very good odds until we were confronted with the reality of real problems in both areas following surgery. Those percentages mean little when you are one of the 5%. Speaking to others who have had similar treatment we suspect that the quoted 5%, in his case, is illusionary.

Don’t get me wrong, I am glad that my cancer was picked up following a routine blood test form my General Practitioner. The consequences of not having been diagnosed are too frightening to contemplate. I know that we have become stronger as a result of my diagnoses and treatments.

There was no Prostate Cancer Support Group in our local area until October 2001. My wife and I have regularly attended this Group and have found it to be of considerable benefit in both a physical and emotional context. The value of the support from these Groups cannot be underestimated. Through the Support Group we both know that there are others who are a lot younger than I for whom the long-term survival prognoses are bleak.

The following information is based on our journey with prostate cancer.

Yours faithfully,

Alan and Gabrielle Moran.
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(a) The delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:

(i) the efficacy of a multi-disciplinary approach to cancer treatment,

I only wish that there had been this type of team approach in operation when I was diagnosed with prostate cancer in 2000. One of the difficulties my wife and I had at that time, was to obtain unbiased information on the types of treatment that were available and the side effects of a particular type of treatment. As an example when we asked the Urologist about Brachytherapy he said it was experimental. Which may still be true in a scientific sense, but to lay people it implied they were still trying out the procedure.

A couple of years prior to being diagnosed I remember reading an article of the dilemmas facing Mr Frank Sartor and his partner at the time of her diagnoses with cancer and their attempts to get unbiased information on the types of treatments available.. He said then, that there was a need for the services of a holistic person who had an overview of treatments, services and outcomes that were available for a particular type of cancer, rather than going to a surgeon who would recommend surgery, or a radiation oncologist who would recommend radiation etc. He is now in the position to do something about holistic information being available as the State Minister with responsibility for the NSW Cancer Institute.

Following the adoption of “A clinical service framework for Optimising Cancer Care in NSW” in 2003 three multi-disciplinary treatment (MDT’s) teams were established in 2004 for breast, lung and colorectal cancers within the Nepean Cancer Care Centre which is attached to Nepean Public Hospital. At that time there was none established for prostate cancer. However one was subsequently established for prostate cancer in late 2004 and operates at Nepean Public Hospital.

These MDT’s are predominantly for the professional development of the specialists where they discuss the appropriate treatment for patients, but to the best of my knowledge the patient has no access to these MDT’s. The patient/consumer what ever we may call them are at least entitled to have access to the same type of consultation as the specialist. After all, there is discussion on the appropriateness of the most suitable treatment for a patient and the patient is informed after these deliberations. This seems to me to be an inequitable situation.

The patient/consumer is confused and bewildered after having been told that they have “the big C”. My specialist gave us a booklet to read on surgery. However, subsequent investigation, usually on the Net, of the types of treatment options available simply creates more confusion.

There is clearly the need for an independent experienced multidisciplinary specialist who can provide an overview of the cancer treatment options available, and the consequences of undertaking a particular treatment to assist the patient and the carer in making an informed decision. In part due to the conflicting opinions expressed in the information currently available, this multidisciplinary specialist has to have experience in a number of treatment disciplines.

All of this has to call into question the legitimacy of a patient being able to give informed consent, eg The Cancer Council of Australia, and therefore all State Cancer Councils are opposed to the use of the PSA blood test as a indicative test, yet all urologists and most G'P's use the test as a precursor of the need for further testing.

I find this attitude of the Cancer Councils to be confusing in that I have heard urologists say that the PSA test is more reliable than the mammogram. None of this un-necessary, confusing, conflicting and misleading information is of any help to patients and their carers trying to come to grips with being told that they have "the big C".

In my case, my urologist as a surgeon recommended surgery. Another specialist I consulted was also a surgeon, their speciality tends to make them biased in advocating a particular treatment. The specialist suggests you seek a second opinion, but he very rarely suggests you contact a consumer group. Unfortunately at the time of my diagnosis there was no Prostate Support Group in operation and we both would have benefited from discussions with others and the treatments that they had.

Yes, you can consult the Cancer Council, I did, and subsequently spoke to another man who had surgery which was good, but with the power of hindsight I would have/should have asked a number of other questions and sought information on other treatment options that were available. You learn from your experiences following treatment. Not all treatment outcomes are good from a patients perspective.

Firstly I believe that a patient's groping in the dark for unbiased information on treatment options for all types of cancers for them as individuals could be answered by a holistic cancer specialist. There would be resistance for this service from specialists, however, the rights of the patient and their access to treatment options should be paramount in their being able to make informed decisions, and subsequently be able to give informed consent to assist them fight their cancer.

Secondly, I believe that any multidisciplinary team formed to deliver services, support and help to patients and their primary carers would be enhanced by the inclusion of a member of the relevant cancer support group. This is based on their experience in dealing in a practical sense with cancer.

(ii) **the role and desirability of a case manager/case co-ordinator to assist patients and/or their primary care givers.**

Had this service been available, my wife and I would have found the help and support of a case manager/case co-ordinator to have been most helpful and more importantly reassuring. I found my urologist almost useless in assisting with the complications following surgery. Unfortunately there are no league tables available to show the performance of specialists and their effectiveness regarding treatments.

Four and a half years after surgery I am still incontinent and impotent. Prior to making our decision we asked the specialist of possible side effects. He told us that in about 5% of his cases there was incontinence and impotence, both most important to ones proper physical and sexual functioning and well being.

Those percentages are of little meaning if you are experiencing these side effects following surgery or radiation treatment. In my follow up visits with the specialist he kept telling me that to give it another 6 months and things would right themselves. I now find out, from specialists attending a Prostate Cancer Support Group that the specialist should have told us at the time of our initial consultations about the need to do pelvic floor exercises as a means of strengthen these most necessary muscles to assist in controlling continence. Some two years after the operation he suggested that I see a physiotherapist specialising in continence. He has been of no help with my impotence.

Based on my experiences I am convinced that a case manager/case co-ordinator would have been better able to assist me and support my wife during the period of our turmoil following surgery.

I now know that the Prostate Cancer Foundation of Australia (PCFA) makes grants available to nurses to receive additional specialist training as prostate nurses. Obviously these especially trained nurses would make ideal case managers/case co-ordinators. We, as patients need to know that they are available.

It would be my belief that a case manager/case co-ordinator would be/should be able to call on the services of a multidisciplinary team to provide the necessary ancillary services be they physiotherapy, psychology, social work, palliative care etc to assist and support the patient and primary care giver. Coming to grips with the reality that you have been diagnosed with cancer is the first hurdle that you both have to overcome before even looking at treatment modalities.

It is also my belief that the role and value of Cancer Support Groups would make a valued contribution to the proper functioning of multidisciplinary teams and on that basis assist the case manager/case co-ordinator.

(iv) differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians, and

In figures released recently by the Cancer Council of NSW we know that more men die in regional Australia from prostate cancer than in the capital and large coastal regional cities. Those that are diagnosed are usually at the advanced cancer stage leading to a painful and early death.

The availability of specialists, prostate diagnostic services and treatment centres is insufficient to provide comparable services to those available on the coastal fringe. I would suspect that there is a great need for increases in all cancer services to Regional Australia.

Men are usually diagnosed with prostate cancer from 50 years onwards. I would therefore suspect that Indigenous Australians are not appearing in the statistics due to their very high death rate to that age. The state of their general health must be of concern to all Australians.

National statistics show that deaths from Breast and Prostate Cancers are almost the same at around 2,600 per annum. The high profile that Breast and Cervical Cancers have as a result of the National Awareness Campaigns funded by the Commonwealth Government is to be commended. Yet the same cannot be said about prostate cancer.

The National Awareness Campaign for Prostate Cancer “Be a Man” was organised by the Prostate Cancer Foundation of Australia and funded by a Insurance Organisation.

The raising of the awareness of prostate cancer is more than likely done by Prostate Cancer Support Groups across Australia through community meetings. One would believe that if there was similar emphasis on the raising of the awareness of prostate cancer and a similar testing regime to that of breast and cervical cancers, that the numbers diagnosed and treated would/could lead to a reduction in the number of deaths. Which has got to be a plus!!.

We, in the Support Group movement are finding that more and more men in their early 50’s are being diagnosed with advanced prostate cancer which can and does lead to an early and very painful death. **Surely the raising of awareness is not such a bad thing if it leads to increased survival.**

Conversely, if it is best practice for the Commonwealth Dept of Health to advocate for and conduct screening for breast and cervical cancers, why is it not best practice for the same Department to advocate for and conduct testing for the second major killer of males, prostate cancer? Where is the equity? The figures of 2,600 deaths from Prostate Cancer each year would/should indicate that there is a need to reduce this toll by raising the awareness of and testing for prostate cancer.

An excellent example of best practice would be the development of “League Tables” on the different types of treatment for cancers, the effectiveness of these treatments, the side effects of these treatments, the competency skills of treatment specialists, and the failure rate of these same specialists.

The private members motion introduced by The Hon. Jim Lloyd, Member for Robertson and seconded by the Hon Wayne Swan, Member for Lillie into the Australian Parliament last year requested amongst other matters that the Commonwealth introduce an education and awareness campaign for prostate cancer.

If best practice is about the reduction of the incidence of all cancers then more has to be done to bring the message home to the whole community.