17 De Salis St.,
WEETANGERA ACT 2614.
17 September, 2009.

Ms. Katy Gallagher, MLA.
Minister for Health,
A.C.T. Legislative Assembly.

Dear Ms. Gallagher,

We have much pleasure in submitting this proposal for the appointment of specialist prostate cancer nurses by the A.C.T. Government. We regard these appointments as a matter of urgency given the rising incidence of prostate cancer among Australian men and the high incidence among men in the A.C.T. and region.

Further information can be obtained from the undersigned. We are also available for consultation and would appreciate being involved in, and informed of, deliberations about this matter.

Yours sincerely,

Peter Daley, Dr. Jim Clough,
President. Past President.
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Additional copies to:

Mr. Jeremy Hanson, Shadow Minister for Health, A.C.T. Legislative Assembly.

Ms. Amanda Bresnan, A.C.T. Greens Spokesperson for Health, A.C.T. Legislative Assembly.

Ms. Mary Porter A.M., Member, A.C.T. Legislative Assembly.

SUBMISSION TO

THE MINISTER FOR HEALTH IN THE AUSTRALIAN CAPITAL TERRITORY GOVERNMENT

CONCERNING THE APPOINTMENT OF PROSTATE CARE NURSES

FROM THE PROSTATE CANCER SUPPORT GROUP – ACT REGION

SUMMARY

This submission indicates the need for additional support for men diagnosed with prostate cancer and their families.

While many of the facilities for the diagnosis and treatment of prostate cancer are available in the ACT region there is considerable evidence that there is a lack of continuity of care.

In particular, immediately after diagnosis many men have difficulty dealing with the fact that they have been diagnosed with cancer, understanding what the diagnosis means, what the alternatives for treatment are and a multitude of other issues which impinge on them personally, and their families.

Evidence is presented of the rising incidence and mortality from prostate cancer and this data is compared with the quite similar data from breast cancer.

In seeking a model by which this continuity of care for men diagnosed with prostate cancer may be provided, the role of the breast care nurse represents an obvious parallel.

There is considerable support in the literature for this model of care, and several major reports support the efficacy of such an approach.

The Prostate Cancer Support Group – ACT Region Inc has financed, from funds raised locally, the university based training of three nurses in prostate care nursing and has plans to fund a further three during semester 2, 2009.

The Support Group respectfully suggests that at least three specialist prostate care nurses should be appointed.

The current high incidence of and mortality from prostate cancer together with the rapid acceleration of these two statistics makes such appointments a matter of urgency.

THE AIMS AND OPERATIONS OF THE PROSTATE CANCER SUPPORT GROUP - ACT REGION INC.

The Prostate Cancer Support Group – ACT Region Inc. is affiliated with the Prostate Cancer Foundation of Australia. All members of the Support Group are volunteers and it does not receive any government financial support. The Group has been operating for over twelve years and has gradually increased its services to men with prostate cancer, their families and to the community in general.

The aims of the Group are;
(a) to provide support, information and advocacy to men and their families impacted by prostate cancer;

(b) to raise awareness in the community about prostate cancer; and

(c) to solicit and receive donations to fund objectives (a) and (b) above.

This has been done in a variety of ways.

A major focus has been raising public awareness about prostate cancer, its detection, the need for early detection and appropriate modes of treatment. During the last two years members of the support group have presented a structured audio-visual program about the diagnosis and treatment of prostate cancer to approximately 45 groups involving about 1100 individuals. Groups involved in this program have included community groups (e.g., Rotary, Probus, Bowling Clubs), Commonwealth and ACT Departments and Instrumentalities (e.g. Australian Federal Police, Department of Immigration and Multicultural Affairs, ActewAGL).

The group has also manned booths at approximately 12 community events (e.g., Murrumbateman Field Days, Queanbeyan Show, the Council of ACT Motor Clubs ‘Wheels’ display) handing out literature and speaking to men and women about prostate cancer. As well as providing information about prostate cancer this literature has given information about the monthly meetings of the support group and indicated how members of the group can be contacted.

The group also has a newsletter that is distributed to about 150 persons within the Region and beyond, mainly electronically, but in hard copy where this is desired. This assists in providing information about events and about recent developments in the treatment of prostate cancer and related conditions.

While fundraising has not been one of the principal activities for our Support Group, as the result of having a good public profile through our awareness raising activities, a number of individuals and groups have provided generous support to PCFA and to our Group.

It is through our monthly meetings and individual contacts, as well as our personal experience of prostate cancer that the longer term members of the group have become aware of the strengths and weaknesses of the avenues for diagnosis and treatment of that disease in the ACT.

THE DIAGNOSIS AND TREATMENT OF PROSTATE CANCER IN THE ACT REGION

At present the diagnosis of prostate cancer in the ACT and surrounding Region is quite good, although a worrying number of general practitioners (GPs) are not proactive in encouraging men at risk of developing prostate cancer to undertake appropriate testing. Some even actively discouraging at risk men.

There are also a number of GPs who refuse to carry out a digital rectal examination (DRE) either for personal reasons or because they lack the skill.

There appear to be adequate facilities for the conducting of biopsies and for pathological analysis of samples. Other tests such as ultrasound, bone, CT and MRI scans are also readily available. Similarly the waiting time to see urologists and radiation oncologists and for subsequent treatment, either as private or public patients are at acceptable levels. The recent retirement of two urologists in the ACT region does pose a threat to the continuing reasonable access to such services.

While, of the mainstream treatments for prostate cancer, open and laparoscopic prostatectomies are available in the ACT, robotic surgery is not currently available. Similarly external beam radiation is available in the ACT, but neither seed implant nor high dose brachytherapy are. This state of affairs has meant that a number of men from the Region have had to travel interstate to secure the most appropriate treatment for their cancer at considerable financial and personal expense. Others have not been able to avail themselves of the most appropriate treatment, generally for financial reasons.

However, the most glaring lack of services is the coordination of the many factors that impact on the man and his family.

THE NEED FOR SPECIALISED PROSTATE CANCER NURSES

It is no surprise that when men are diagnosed with prostate cancer they are not always very receptive to the information imparted to them by their GP or oncology specialist. It is common for men who attend the Group for the first time or who approach the contact persons within the Group to be quite unsure of details of their diagnosis and their prognosis. Many are also unsure of the treatment options available and where they are available, their cost, likely side effects of these treatment options, and many other relevant issues.

Although prostate cancer tends to strike older men, many have had very little experience of surgery or other radical treatments, not having undergone operations or experienced hospitalisation. Those men especially, but all prostate cancer sufferers would benefit from knowing the specifics of their treatment.

Many also suffer a great deal of mental trauma, worrying about their personal outcomes and the impact on their family and significant others. Incontinence and impotence are significant issues for many men.

The experience within this support group accords well with the issues raised in the 2003 report concerning psychosocial care of adults with cancer (National Breast Cancer Centre and National Cancer Control Initiative. 2003. Clinical practice guidelines for the psychosocial care of adults with cancer. National Breast Cancer Centre, Camperdown, NSW.)

With special reference to prostate cancer, these issues are;
Emotional and social issues,
Psychological issues, including body image, sexuality, interpersonal problems, new relationships post diagnosis, stress and adjustment reactions/severe emotional distress, anxiety, depression and PTSD,
Physical issues, including nausea and vomiting, pain, fatigue, fertility, incontinence, bowel dysfunction, malnutrition.
Practical issues, including treatment, travel and accommodation costs, loss of income,
Towards end of life issues,
Survival issues. (pp. 12 – 14)

This publication also comments on the effectiveness of specialist oncology nurses.
‘In the area of breast cancer, a new approach to achieving continuity of care has been developed. Specialist breast nurses are advanced practice nurses whose skills include, coordination of care; counselling; provision of information and support; clarifying or reinforcing information; providing continuity of care; and facilitating specialist referral.’ (p. 78)

It also notes that: ’Specialist breast nurses are uniquely positioned to provide support and practical assistance to patients throughout the various stages of their treatment and have been found to be effective and beneficial in the ongoing care of the patient. In a recent demonstration project conducted by the NBCC among women with breast cancer; 80% of respondents believe specialist breast nurses made a significant contribution to their care and 99% reported they would recommend seeking treatment at a centre that provides a breast nurse.’ (p.78)

It continues ’Because of the success in the area of breast cancer there is a growing interest in specialist nurses and the potential for developing this role with other cancer groups such as individuals with prostate and gynaecological cancers. These roles are not yet as developed as that of the breast care nurse, and further research is required in this area although emerging evidence suggests that prostate care nurses are seen as very acceptable sources of information and support for men with prostate cancer.’ (p78)

Unfortunately specialist prostate cancer nurses are not readily available to men and their families in the ACT and Region. There is strong evidence that there is an unmet need for such nurses and that the need will increase.

A recent Australian publication has provided information about the incidence of prostate cancer among Australian men (Australian Institute of Health and Welfare/ Australasian Association of Cancer Registries) Cancer in Australia: an overview, 2008, December 2008, (AIHW/AACR), and the Senate Select Committee on Men’s Health: Report (email version of 29 May 2009 available at
http://www.aph.gov.au/Senate/committee/menshealth_ctte/index.htm
(Men’s Health Report)).

This report provides the most recent information concerning the incidence of and mortality rates for cancer among Australian men and women during 2005, and projections for this data from the period 2006 to 2010.

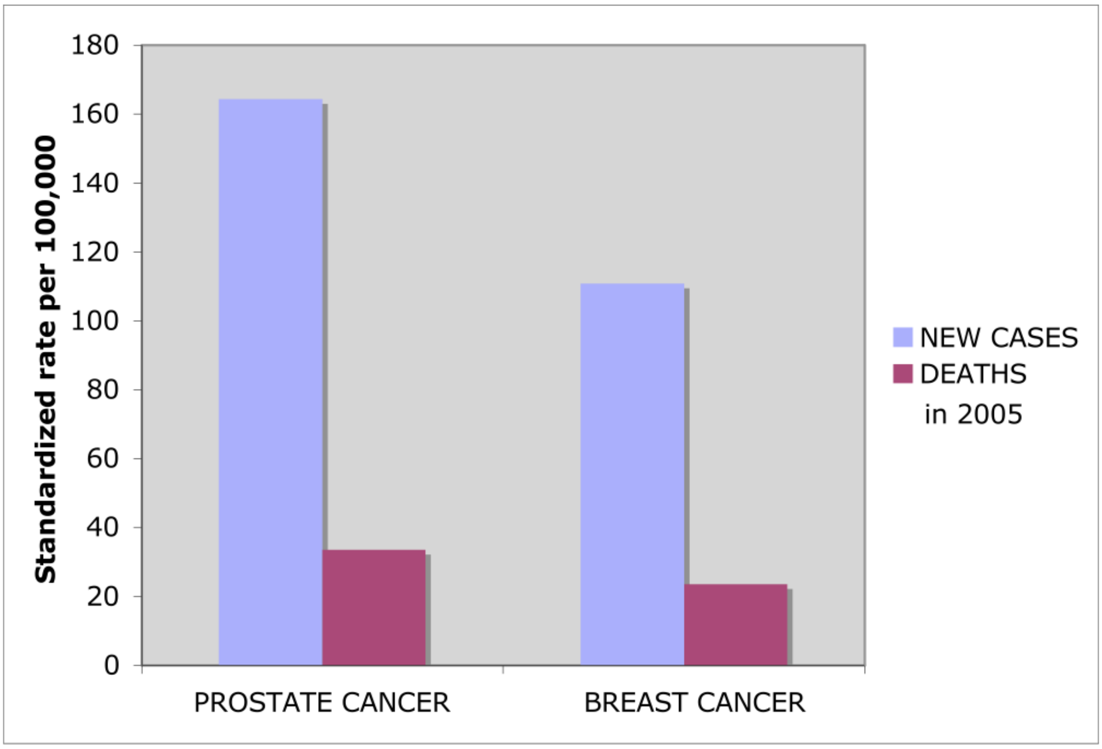
As the incidence of prostate cancer and breast cancer are comparable and as experts in the field recognise that many of the needs of the two groups are analogous it is useful to compare the incidence of the two cancers. The following table summarises the information for prostate and breast cancer. See also Figure 1.

Table 1.
Incidence of, and Mortality from, Prostate and Breast Cancer.

	Actual 2005	Projected Annual Increase 2006 - 2010	Projected for 2010
Number diagnosed with prostate cancer	16349	939	19775
Prostate cancer deaths	2949	84	3366
Number diagnosed with breast cancer			
Female	12170	311	14017
Male	95	3	110
Breast cancer deaths			
Female	2707	38	2930
Male	19	0	19

Comparing the incidence of prostate cancer among males with that of breast cancer we can see that it is 34% higher in 2005 and it is projected to be 41% by 2010. Mortality from prostate cancer is 9% above that of breast cancer in 2005 and is projected to be 15% by 2010, that is by next year.

These are of course Australia wide figures, but the incidence of prostate cancer among ACT men is the second highest of all states and territories (154.1 per 100,000) while the incidence of breast cancer among ACT women is the highest (129.2 per 100,000).



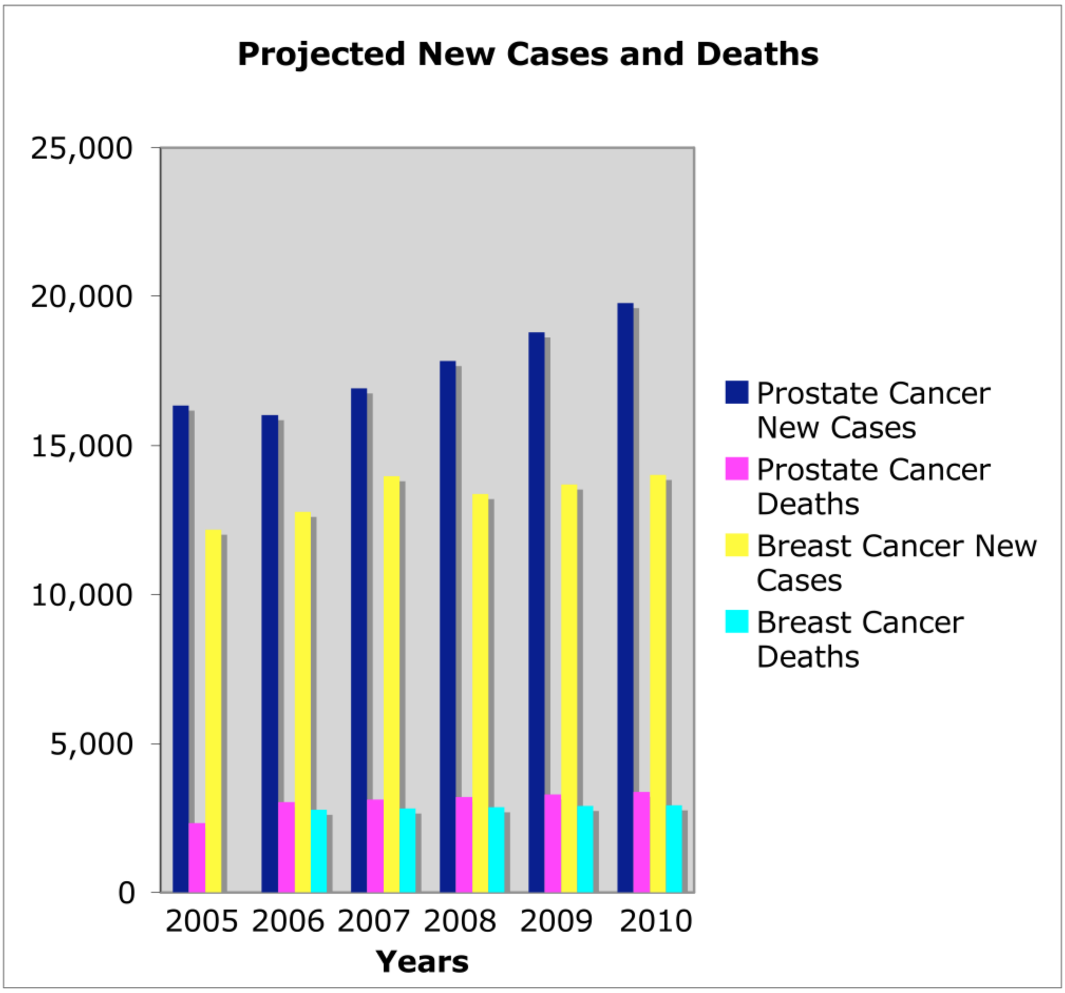


FIGURE 1. PROSTATE AND BREAST CANCERS IN AUSTRALIA

It is clear that both prostate and breast cancer are currently important health issues for the residents of the ACT, and that it will be necessary to increase the level of resources devoted to the detection and treatment of these diseases.

The typical process for being diagnosed and treated for prostate cancer is having a PSA test and/or a DRE by a GP. With regular testing changes in PSA may suggest an interim diagnosis of prostate cancer. The GP can use other tests such as free PSA and a DRE to support such a diagnosis. This generally results in a referral to a urologist and the completion of a biopsy if prostate cancer is suspected.

If the biopsy confirms the presence of prostate cancer it is generally the urologist who informs the man of this diagnosis. Many men report that they were delivered this information in a manner that left them very distressed and with little or no understanding about their prognosis and options for treatment.

This does not always mean that the urologist or other medical practitioner has been remiss (although this explanation cannot be ruled out), but the shock of being diagnosed and the lack of time the practitioner can spend with the newly diagnosed man may also be factors.

While the availability of appropriate cancer specialists has been satisfactory recent retirements among the ranks of the urologists are likely to make it even more difficult for them to spend an appropriate amount of time with their patients.

A more cost effective solution would be to provide specially trained prostate cancer nurses to provide support to men diagnosed with prostate cancer prior to their treatment, during their treatment and during their period of recovery.

The Senate’s Men’s Health Report supports this approach.

After noting the Commonwealth Government’s support for breast cancer nurses the Report recommends (Section 4.58) that
‘In view of the various factors discussed in this chapter; incidence, mortality, difficulties surrounding diagnosis and treatment, the psychological impact on patients and their families and regional variations in outcomes, it is clear that a similar need exists among prostate cancer sufferers and their families. A program to appoint specialist prostate cancer nurses should be established.

The committee recommends that the Commonwealth Government expedite funding for the provision of specialist prostate cancer nurses, particularly in rural and regional Australia.'

(The complete Chapter 4 'The Prostate' is included as Appendix A.)

The ACT Government has already recognized the need for specialist breast cancer nurses by appointing three such nurses to provide support for those diagnosed with breast cancer, whether they be public or private patients. This does not seem to be an excessive number.

Given that the incidence of prostate cancer is higher than that of breast cancer, and that it is increasing at a more rapid rate, there is a strong case that at least three prostate cancer nurses should be appointed by the ACT Government. It would be anticipated that the services of these nurses would be available to public and private patients.

At present the only specialist prostate cancer nurse employed by the ACT Department of Health, is a Prostate/Urology Nurse Co-ordinator, at Canberra Hospital and the incumbent has provided support for prostate cancer sufferers including an excellent information leaflet. However, this position involves considerable administrative functions and covers the whole field of urology. Clearly the incumbent is not able to meet all the demand for specialized prostate cancer nursing in the ACT and Region.

There is also a trained and experienced prostate cancer nurse employed by Calvary John James, but she is employed as a general nurse and has very little opportunity to provide this vital service to men with prostate cancer.

As the result of our fund raising we have been able to provide financial support to three local nurses to undertake a specialized unit in prostate cancer nursing at Latrobe University during semester 1, 2009. All three nurses have completed the unit requirements.   It is anticipated that a further three nurses will be able to undertake the course during semester 2, 2009.

In related areas, there is the local Continence Clinic that provides a very necessary service to the residents of the ACT and Region, many of them prostate cancer patients, but these practitioners are not able to coordinate the treatment of prostate cancer patients.

We believe that the above demonstrates the need for the appointment of at least three specialist prostate cancer nurses by the ACT Department of Health as a matter of urgency.

While job descriptions for these positions are clearly the role of the Department, some guidance as to specifics of this role can be found at Appendices B and C.

Appendix A.

Chapter 4

The Prostate

4.1 Submissions and other evidence taken by the committee concentrated overwhelmingly on two matters - diseases of the prostate and depression. In this chapter the committee considers the issues with regard to the prostate – research and research funding, diagnosis (including testing and screening issues), treatment and education and awareness.

4.2 The prostate gland is found only in males. It surrounds the urethra where it leaves the bladder and produces a fluid which is a component of semen. The prostate is vulnerable to a number of diseases – particularly acute and chronic prostatitis, prostatic enlargement and cancer. Chronic prostatitis and benign prostate enlargement are considered later in this chapter.

Prostate Cancer

4.3 Cancer of the prostate is a significant health problem and, with the ageing of the population it is likely to become the leading cause of death from cancer in men in the near future.[1] Prostate cancer is the most commonly diagnosed cancer in Australia,[2] the fifth largest cause of death among men, and, after lung cancer, the second most common cause of death from cancer. It is predicted that the rate of prostate cancer will rise by 3.1 per 100 000 males or 939 extra cases per annum.[3]

4.4 Over the age of 51 prostate cancer becomes the most common cancer for the remainder of a man's life. [4] Regrettably, despite the incidence of this disease there has been a tendency to dismiss it as an inevitable part of the process of ageing:

...there is a concern amongst clinicians that treat prostate cancer and researchers that because it can be labelled as a disease of old men it is not as important. Firstly, younger men can develop prostate cancer, with devastating consequences. That comment still occurs and it is an ageist comment. ... As a practising clinician I do not consider anyone in their 70s to be elderly but have an expectation that men will not lose years of their lives or have the morbidity that can occur from disseminated prostate cancer.[5]

4.5 In this context it is important to remember that, for the purpose of medical statistics, 75 is considered a 'normal' life span, that male life expectancy is now 78 years and that a decision to raise the retirement age to 67 has just been announced. Thus prostate cancer is, and will remain, a significant health issue for men of working age.

4.6 The committee believes that the case for secure long-term funding for research into diseases of the prostate is beyond dispute. The incidence of prostate cancer and its projected increasing incidence is sufficient justification in itself for a considerable research effort and enhanced treatment and support services.

4.7 The benefits that can flow from research which provides for a better understanding of a disease and hence earlier diagnosis and better treatment can be shown by the declining mortality rates for a number of 'common' cancers. Colorectal cancer mortality has fallen by about 40% since the 1980s largely due to improved early diagnosis and treatment; cervical cancer mortality has declined by some 75% since the 1960s since the introduction of the pap smear and deaths from lung cancer in males has fallen by nearly 40% from its peak around 1980 as a result of the reduction in smoking and improved treatment.[6]

4.8 It is difficult to estimate the level of funding for research into prostate cancer because it comes from a range of sources. Specifically with regard to funding through the Commonwealth's principal funding body for medical research, the National Health and Medical Research Council (NHMRC) prostate cancer research has lagged behind breast cancer research. In the years 2000-2008 funding for prostate cancer was $44.5 million compared with $88.9 million for breast cancer.[7] Given that the death rates from these two cancers are similar, that the incidence of prostate cancer is actually greater and that projections for the increased incidence are, by some margin, higher than for any other type of cancer[8] there is a very good case for an increase in funding in this area.

4.9 Prostate cancer remains relatively poorly understood and thus presents particular problems of both diagnosis and treatment. As an internal organ, changes to the prostate are not immediately obvious and, at present, no definitive test short of a biopsy (which extracts tissue samples from the prostate for examination) is available.

4.10 The committee was told by a number of witnesses at its hearings that, where a cancer does exist, the nature of that cancer is also difficult to determine. Prostate cancer can be largely passive or very slow growing and have no noticeable affect on a patient (hence the saying that more men die with it than of it). Alternatively the cancer can be aggressive and metastasise (grow beyond the prostate itself) leading to serious illness and death.

4.11 At present the ability to determine which type of cancer a patient has is limited:

The disease is highly variable. You can have two cancers that look alike down the microscope. One of them will be quite indolent and the other one will be quite aggressive. ...and we have got no marker for that at all.[9]

4.12 This problem is compounded by the fact that cancer may be dispersed throughout the prostate and have different characteristics:

The thing is that it is a multifocal disease. It is, to a large degree, in the periphery of the prostate but there are different cancer foci and it is believed that they probably arise independently and therefore may have different propensities for aggressive progression of the disease.[10]

4.13 The difficulties associated with diagnosis flow on into treatment. At present there are limited treatment options, particularly for non-invasive therapies.

A diagnosis of prostate cancer also impacts on quality of life, due to the current inability to determine and advise the sufferer on the likely course of his disease. This leads then to a combination of clinical and psychosocial impacts....[11]

Research Priorities

4.14 It was put to the committee by the Institute of Biomedical Research and Innovation that the priority areas for research into prostate cancer are:

- Development of new predictive and diagnostic tools to identify men at increased risk of developing PC and enhance early detection of the disease;
- Development of new prognostic markers to distinguish between aggressive and nonaggressive cancers to inform treatment options and minimise impacts on patient quality of life; and
- Development of new therapeutic options that target the genetic and biomolecular factors that underlie specific prostate cancer types.[12]

These priorities were reflected in other submissions from professional groups.

4.15 If significant advances are to be made in the identification and treatment of prostate cancer, research must be supported over the whole spectrum of relevant activities. Professor James Best summarised these as:

> ...biomedical laboratory-based discovery research; clinical research, which goes out of the laboratory to involve patients in the research; population based research, where we might look at the prevalence of prostate cancer and whether it is increasing, decreasing et cetera; and finally health services research, which is how is prostate cancer treated and how might we improve the treatment.[13]

4.16 The committee strongly supports continued and increased funding for organisations engaged in research and other activities, such as health promotion and public education across all these areas.

The Australian Prostate Cancer BioResource

4.17 Underlying progress in all these areas is a need for research material, specifically tissue collected from prostate cancers.

> Medical researchers will undoubtedly uncover the secrets of prostate cancer variability that give rise to this complex disease. Discoveries will come from studying the biology, pathology and clinical outcome of tissues from a large number of men with the disease,... More importantly, the more cases studied the more likely we will unravel the full spectrum of disease...[14]

4.18 Only by being able to examine a large number of tissue samples and follow the progress of the disease over a period of ten to twenty years will researchers be able to make progress:

> ... prostate cancer tissues really form the basis for all of Australia's prostate cancer research, into biomarkers of diagnosis, prognosis—that is, outcomes—and therapeutic response.[15]

4.19 A further reason for the importance of human tissue in prostate cancer research is that the use of laboratory animals does not provide a practical alternative:

> The reason that biobanks and specimens taken from men are so important to a biomedical researcher in prostate cancer is that you do not have mouse models to work with. Mice do not get prostate cancer. You can make them do that if you genetically manipulate them, but it is not something that occurs spontaneously.[16]

4.20 The importance of being able to follow the development of a disease in individual patients is a product of the currently unpredictable nature of the disease:

> ...approximately 30 per cent of men operated on will fail that treatment. Their cancer will have already escaped the prostate by the time they are operated on. We cannot pick these people. Those patients will relapse in about three to seven years after the operation.[17]

4.21 The principal prostate tissue collection in Australia is the Australian Prostate Cancer BioResource, established in 2004, which currently collects tissue samples from more than 10 hospitals throughout Australia.[18] The committee is particularly concerned to ensure that this BioResource receives secure, long-term funding to enable it to carry out the full range of activities in support of research. It was initially funded by the Commonwealth Bank of Australia, Prostate Cancer Foundation of Australia and Andrology Australia and has received funding from the NHMRC. The NHMRC grant runs until 2009 and renewal is currently under consideration.

4.22 The committee is advised that the BioResource faces a number of limitations imposed by resources which prevent it achieving its full potential. Financial constraints act at both the collection and research stages. Consent of patients to participate in the program has to be obtained and tissues have to be collected and stored according to uniform procedures. At present the BioResource relies,

> ...on the goodwill of the institutes, the medical schools that are associated with the institutes and the pathologists who are doing things for us gratis, although they are very busy.[19]

4.23 As a result of practical arrangements within hospitals, the scheduling of operations and availability of pathologists for example, tissue is not collected from a proportion, up to 30%, of men who have consented to participate in the program.[20]

4.24 The BioResource needs to maintain the current rate of tissue collection until at least 2014 to ensure that there is a sufficient number of tissue samples and that these samples have been followed over a long period of time.

4.25 At the research stage the BioResource would be much more effective if it could produce a greater range of blood and tissue products to supply to researchers. As described in its submission the production of serum and plasma extracted from blood, DNA from blood cells and prostate cancer tissue, RNA from prostate cancer tissue, and microarrays of tissue cores of selected prostate pathologies and disease outcomes. These materials are used for the discovery of markers of diagnosis, prognosis and therapeutic response, and for determination of cancer-related mutations and predictive genetic variations. [21]

4.26 In addition to these research activities the BioResource requires an accessible web-linked database which would enable researchers to "... view the collection on the database online to determine which patient tissues are relevant to their research study...".[22]

4.27 The committee is advised that the current level of funding,

...provides part of [the Project Manager's] salary and the salaries of four tissue collectors, one at each node, and a small amount of maintenance for each of those nodes. It is really only about half what we want.[23]

4.28 It should be noted that staffing of the BioResource has been delayed and the National Project Manager only works part-time to try and ensure that existing funding can be made to last until the end of 2009. [24]

4.29 The question of some element of self-funding of the BioResource through cost-recovery was raised in the committee's hearings. This raises the conflict between putting a price on a product to ensure that users value it appropriately and discouraging its use by setting a price that is a disincentive to use. The committee was advised that it does not charge university and other non-profit institutions. At present it does not supply the private biotechnology industry but should it do so in the future then the issue of charging for tissue will be reviewed.[25]

4.30 The committee does not wish to make a recommendation with regard to a precise level of funding for the BioResource; that is a matter for government and the relevant professional funding bodies. However the committee would wish to endorse the importance of the BioResource as fundamental to the conduct of the very necessary research into prostate cancer.

The committee recommends that the Commonwealth Government ensure that the Australian Prostate Cancer BioResource is provided with sustainable funding at a level that would enable it to complete its tissue collection and carry out the necessary work in support of prostate cancer research outlined in this chapter.

4.31 An important aspect of research is the translation of that research into better patient outcomes. It was explained to the committee that the institutional pressures of attracting research funding and building a professional reputation can come into conflict with the need to engage with the general community either by publishing in non-specialist media, working through groups such as Andrology Australia and the Prostate Cancer Foundation or through community groups such as Rotary. At present the incentives, for example the ranking of publications in journals, tend to favour the former activity.[26]

4.32 The committee has no ready answer to this problem. However it does emphasise the need for continued support for organisations such as the prostate Cancer Collaborations, Andrology Australia and the Prostate Cancer Foundation as vehicles for bringing together researchers from different areas, facilitating coordination of research and providing the lay reader with accessible information on technical matters such as prostate cancer testing and screening.

4.33 It would also be valuable if 'community outreach', which is encouraged by research institutions, could also be given more weight in ranking researchers and making funding decisions.

Screening and Testing[27]

4.34 This is a key area for research into prostate cancer. An effective screening program can have a significant impact on the morbidity and mortality of a disease. The three national cancer screening programs operating in Australia at present are for breast cancer, cervical cancer and colorectal cancer. Deaths from each of these diseases have been reduced considerably since the introduction of screening programs - cervical cancer deaths have halved from 4.0 deaths per 100,000 women in 1991 to 1.9 deaths per 100,000 women in 2006; deaths from breast cancer have decreased from 31 per 100,000 in 1991 to 22 per 100,000 in 2006.[28] The national screening program for colorectal cancers is too recent to have yielded significant results.

4.35 As indicated above prostate cancer can take a number of forms with widely varying prognoses. The ability to diagnose the disease at an early stage and to distinguish the various types of cancer and treat them appropriately is vital. The current inability to do so leads to a situation where,

...men [are] being over-treated for cancers that they do not need to be treated for, but we have at least 3,000 men a year who are not getting treated, because they are dying from it. They probably could have been saved if we knew more about what sort of cancer they had and that they needed radical treatment. That is the number one need...[29]

4.36 The question of population based screening for prostate cancer using the Prostate Specific Antigen (PSA) has been the subject of considerable research and debate both in Australia and internationally. An editorial in the Medical Journal of Australia (MJA) commented "A particular characteristic of the debate has been the polarisation of views...to the point where, at times, constructive debate has been constrained".[30]

4.37 Tests which provide a reliable indicator of the presence of cancer and enable clinicians to distinguish aggressive from indolent cancers would have a significant impact on prostate cancer treatment. To be effective the method of screening should have a high level of sensitivity, meaning that it indicates positive results with a high level of reliability (and yields a low level of 'false negatives' which result in cases of the disease being missed). The method should, ideally, also have a high level of specificity; that is it should identify those who do not have the disease with high reliability and thus avoid 'false positives' – indicating that people who are in fact disease free have the disease which may lead to further, unnecessary invasive testing or treatment.

4.38 The MJA editorial referred to above identified the problems as arising from,

...the fact that PSA is not a test for prostate cancer and has no threshold level providing a high sensitivity and specificity...a raised PSA level often commits men to the invasive procedure of transrectal ultrasound (TRUS) guided biopsies.

and concluded that,

If the diagnostic process were non-invasive and treatments with curative intent were not associated with significant unwanted effects, few would quibble about whether it is appropriate to be tested.[31]

4.39 Two recent studies, one in the United States and the other in Europe, have produced conflicting results and interpretations and as a consequence, did not provide conclusive results that might have settled the debate.[32] Andrology Australia drew three conclusions from the results of these studies:

←The results of these studies are relevant to Australian clinical practice and provide the best evidence to date that there is a significant level of uncertainty about the use of PSA test as a population-wide screening marker for prostate cancer;

←Both studies highlighted the issue of over diagnosis as a result of screening and the consequent interventions (and side effects) that would not occur otherwise;

←The studies highlight that newer and more specific prostate cancer markers are needed before an effective population-wide prostate cancer screening program could be recommended or implemented.[33]

←

4.40 As will be discussed further below, treatment for prostate cancer can be invasive and carries with it a number of risks. Thus when evaluating the utility of a screening program it is necessary to compare the outcomes of unnecessary treatment, which may result either from false positive results or from over-treatment in the absence of a clear understanding of the particular cancer being treated, with the benefits of mass screening.

4.41 At present it is the general consensus among medical scientists and the Cancer Councils in Australia is that the PSA does not meet these criteria and that, consequently, population screening using the PSA would not be justified.

4.42 Developing a better understanding of the relationship between PSA results and prostate cancer was given as an example of the sort of research that would be facilitated by the proposed longitudinal study on men's health. "One of the biomedical parameters that we would undoubtedly collect in that longitudinal study could be PSA levels from these men. Then that would give you exactly the information that you would need and it would be informative for people to know what does happen to people’s PSA levels and what did happen to those men in terms of their tumour".[34]

4.43 However testing for prostate cancer where a man has general symptoms or a family history or simply a desire to monitor their own health status should be encouraged. Testing currently relies on a combination of a PSA test and digital rectal examination. Should these tests indicate the presence of an abnormality of the prostate then the patient would be referred for a biopsy, which is the only definitive test for prostate cancer that is currently available. The Prostate Cancer Foundation recommends that all men, from [age] 50 onwards would go to his GP and have a conversation about prostate cancer. If they are concerned about prostate cancer, they should have the blood test, the PSA, and they should also have a physical digital rectal examination to feel whether there is any growth on the prostate.[35]

4.44 The committee endorses the efforts of the Cancer Councils, Andrology Australia and the Prostate Cancer Foundation to make men aware of the importance of seeking medical advice should they have an indication of a problem with their prostate or any of the risk factors, such as family history, which might suggest an elevated risk.

Treatment

4.45 The significant variations in the behaviour of prostate cancer and the difficulty in identifying the probable behaviour of the cancer in the individual patient lead to considerable difficulties with treatment; "The issue for prostate cancer is that we do not know which men to treat..., because we do not have markers that are prognostic."[36] This can lead to confusion and anxiety for patients and their families and may contribute to people undergoing unnecessary or inappropriate treatment.

...we were seeing too many patients coming into our clinics not knowing what their treatment options are. We work in a urology department, so we offer surgery and that is all we offer. Unfortunately, men were coming into the clinic and not being aware that they could have a whole plethora of other treatment options, including radiotherapy and cryoablation—a whole range of different things.[37]

4.46 The committee is not qualified to canvass the relative merits of various treatment options. However it did receive a considerable volume of evidence about the impact on patients of having to make decisions on treatment when faced with a range of options and in many cases insufficient support and advice:

...there are a large number of treatment options available for prostate cancer patients and, from a psychological point of view, this can be a very daunting task. Patients are often asked to make their treatment decision themselves, so without specific guidance from their treating urologist or doctor. Often patients and their families can feel a sense of paralysis around which decision to make.[38]

4.47 A second source of anxiety is the range of morbidities which can result from treatment including:

failed cancer control, incontinence of the bladder or the bowel, sexual dysfunction and psychological trauma. These morbidities seem to have a very big impact in terms of patient quality of life later on down the track and also how they cope with these difficulties psychologically.[39]

4.48 In evidence to the committee representatives of beyondblue made a similar but more general point:

> We are now doing a lot more work in the areas of cancer, such as prostate cancer, and major operations....The surgeon does a good job but no-one is looking after the mind of the person. ...We are not very sophisticated in the holistic medical approach as opposed to dealing with specific individual issues. I think that is an area where we have to make a great deal of inroad in the years to come.[40]

4.49 This is a major health issue. The committee heard that a large survey of patients in NSW found that over 50% of patients had some psychological support need and that just under 50% had a need for support relating specifically to changed sexual functioning after treatment for prostate cancer.[41] Prostate cancer sufferers also suffer from depression at 2 to 3 times the community average and general psychological disorders are present in between 25% and 47% of cases. Some studies also indicate that suicide is more prevalent among older men with prostate cancer, perhaps as much as four times more common.[42]

4.50 Support for patients and their families both at the time of a diagnosis of prostate cancer and in the longer term as they undergo treatment and live with the results of it is clearly an area requiring much greater attention.

> ...in our work running support groups for men with prostate cancer that there was consistent feedback from men saying that they did not have enough support around the time of diagnosis, they did not know about the different support agencies, they did not know that there were different treatment options, they did not know that there were treatment options for sexual dysfunction or where to get pads—a whole range of different things that they just felt they were not being provided information about.[43]

4.51 The efforts of the various organisations which seek to promote public awareness of all these problems have made a significant difference. The quality of information that is available is excellent as are the links to support groups. However more needs to be done to reach all prostate cancer patients and to maintain contact with them.

4.52 During its hearings the committee was advised that a pilot project to test a National Prostate Cancer Information Pack was underway. This is an initiative of the Prostate Cancer Foundation and of practitioners in the field. The pack was modelled on the Breast Cancer Foundation's My Journey kit which is distributed to all patients at the time of a diagnosis of breast cancer. The purpose of the pack is to provide "...credible, non-biased and consistent information about treatment options and ongoing quality of life issues in the context of localised prostate cancer". [44]

4.53 The report of the pilot project indicates almost unanimous support for the pack among patients and a strong support for the major components. To be effective approximately 18 000 Packs would have to be distributed every year.[45]

The committee recommends that the Commonwealth Government provide funding to the Prostate Cancer Foundation to ensure that the Prostate Cancer Information Pack program proceeds.

4.54 Outcomes for patients diagnosed with prostate cancer vary considerably depending on place of residence and income. Patients in rural and regional areas have a 21% greater mortality than those in capital cities. Mortality is also related to income, with significantly higher mortality rates from prostate cancer among socially disadvantaged men.[46] These figures reinforce the need for improved services to be provided throughout Australia.

4.55 Health services in regional and remote Australia generally suffer from "...larger client capture areas, smaller populations, fewer general and specialist medical professionals per population, and fewer services". [47] While the provision of advanced hospital based services can only be addressed by improving patient transport and support services to ensure that they receive high quality treatment, local services providing education and awareness programs to encourage men to seek medical advice and better support services, post-diagnosis should be provided through regional hospitals, health centres or general practice.

4.56 The committee notes, and fully supports, the Commonwealth Government's support for a program to place specialist breast cancer nurses in health centres predominantly in rural and regional Australia. The program, developed in collaboration with the McGrath Foundation, is to provide:

...specially trained registered nurses...[to] provide vital information, care and practical and emotional support to women diagnosed with breast cancer, their families and carers.[48]

4.57 The Prostate Cancer Foundation has been providing scholarships to nurses undertaking training in the treatment and support of prostate cancer patients for some years but there is no program to appoint prostate cancer nurses nationwide. The committee is advised that PCFA is undertaking a study of the viability of such a program.

4.58 In view of the various factors discussed in this chapter; incidence, mortality, difficulties surrounding diagnosis and treatment, the psychological impact on patients and their families and regional variations in outcomes, it is clear that a similar need exists among prostate cancer sufferers and their families. A program to appoint specialist prostate cancer nurses should be established.

The committee recommends that the Commonwealth Government expedite funding for the provision of specialist prostate cancer nurses, particularly in rural and regional Australia.

Non-cancerous diseases of the prostate

4.59 Benign prostate enlargement is a very common but not life-threatening condition. It is estimated to affect 25% of men in their 40s increasing to some 75% in their 70s. It can be little more than a source of discomfort but if left untreated may affect the functioning of the bladder and, in extreme cases, kidneys.[49] Various treatments are available, ranging from drug therapies to surgery depending on severity. Bacterial prostatitis is the result of infection and, again, can be treated with drugs or surgery depending on the severity of the condition.

4.60 Chronic prostatitis, non-bacterial inflammation of the prostate, is poorly understood in Australia, even by doctors and is certainly under-reported. Evidence to the committee suggests that "...awareness of the condition and its treatment is still poor, despite its prevalence and severity"[50] and affects between 10 and 20% of men in Australia.[51]

4.61 In extreme cases it can be the cause of severe pain and leave its sufferers leading 'lives of quiet desperation'. It may be a result of inflammation of the prostate or of muscle tension in the pelvic area and can be alleviated to some extent by anti-inflammatory drugs or physiotherapy.

4.62 All of these conditions are susceptible to treatment and benign prostate enlargement and bacterial prostatitis can become serious problems if left untreated. They are much more common than prostate cancer. However men may be discouraged from seeking medical advice when experiencing symptoms because of a fear of a cancer diagnosis. This emphasises the importance of greater awareness of the various diseases that may affect the prostate both among the general public and general practitioners and of encouraging men to seek medical advice at an early stage.

References

[1] The Victorian Prostate Cancer Research Consortium (VPCRC) estimates that diagnoses of prostate cancer will double by 2020. VPCRC submission, p.1. With the decline in smoking, the mortality from lung cancer in men is declining.

[2] AIHW, Cancer in Australia: an overview, 2008, p.4. "The five most common cancers were prostate cancer (16,349 cases), colorectal cancer (13,076), breast cancer (12,265), melanoma of the skin (10,684) and lung cancer (9,182). These five cancers accounted for over 61% of all diagnoses."

[3] ibid., p.16

[4] AIHW, Cancer in Australia, op cit, p.vii

[5] Prof. J. Best, Chair, Victorian Prostate Cancer Research Consortium, committee transcript, 9 April 2009, p.41

[6] AIHW, Australia's Health, op cit, pp. 45-46

[7] NHMRC funded research into cancer and other malignant neoplasms 2000 – 2008, the Cancer Dataset, http://www.nhmrc.gov.au/grants/dataset/disease/cancer.php (accessed 14 May 2009). In making this comparison the committee does not wish to engage in any 'men v women' debate. The similarity of death rates from the two diseases and a range of other matters makes this a valid comparison.

[8] AIHW, Cancer in Australia, op cit, p.16

[9] Associate Prof. D. Horsfall, National Project Manager, Australian Prostate Cancer BioResource, committee transcript, 30 April 2009, p.4

[10] ibid., Prof. D. Horsfall. p.8

[11] Australian Prostate Cancer BioResource, submission 22, p.1

[12] Queensland University of Technology, Institute of Health and Biomedical Innovation (IHBI), submission 52, p.1

[13] Prof.J. Best VPCRC, op cit, p.41-42

[14] Australian Prostate Cancer BioResource, submission 22, p.1

[15] Prof. D. Horsfall, op cit, 30 April 2009, p.2

[16] Prof. G. Risbridger, Monash Institute for Medical Research, committee transcript, 8 April 2009, p.28

[17] ibid., p.4

[18] Other collections are held by researchers in Victoria and Western Australia.

[19] Prof. D. Horsfall, op cit, p.7

[20] ibid., p.3

[21] Australian Prostate Cancer BioResource, submission 22, p.3

[22] ibid., p.3

[23] Prof. D. Horsfall, op cit, p.7

[24] ibid., p.7

[25] ibid., p.11

[26] This issue is considered in more detail in the committee transcript, 8 April 2009, pp.32-34

[27] The committee has used the term screening to refer to the surveying of populations who have no symptoms but are selected on the basis of some general factor such as sex or age group, for example taking a pap smear or carrying out mammography, and testing to refer to a test administered to a patient showing symptoms.

[28] AIHW, Cancer in Australia, op cit, p.viii

[29] Dr C. Hovens, VPCRC, committee transcript, 9 April 2009, p.43-44

[30] Medical Journal of Australia, 2007; 187(9):501-502

[31] ibid.

[32] See discussion of these studies at, Doubts raised over US study on prostate cancer screening test, Urological Society of Australia and New Zealand, 24 March 2009; Prostate Cancer Screening, ABC Health Report, 23 March 2009 http://www.abc.net.au/rn/healthreport/stories/2009/2520425.htm (accessed 14 May 2009)

[33] Jury still out on PSA testing, Andrology Australia, 3 April 2009, http://www.andrologyaustralia.org/pageContent.asp?pageCode=WHATSNEW1742 (accessed 14 May 2009)

[34] Prof. V. Marshall AC, Centre Director, Freemasons Foundation Centre for Men’s Health, University of Adelaide, committee transcript, 30 April 2009, p.46

[35] Mr A. Giles, Prostate Cancer Foundation of Australia, committee tran-

script, 8 April 2009, p.84

[36] Prof. G. Risbridger, committee transcript, 8 April 2009, p.35

[37] Dr. A. Wootten, Department of Urology, Royal Melbourne Hospital, committee transcript, 8 April 2009, p.41

[38] ibid., p.37

[39] ibid.

[40] The Hon. J. Kennett, op cit, 9 April 2009, p.3

[41] Dr. A. Wootten, op cit, p.38. These findings come from a NSW Cancer Council study.

[42] Prostate Cancer Foundation of Australia, National Prostate Cancer Information Pack, Pilot, Final Report (April 2009), p.7. The introduction to this report provides a useful summary of recent research into the psychological impact of prostate cancer.

[43] Dr. A. Wootten , op cit, p.41

[44] National Prostate Cancer Information Pack, op cit, p.4

[45] This figure is based on the number of prostate cancer diagnoses per year.

[46] Prostate Cancer Foundation of Australia, submission 72, p.2

[47] AIHW, Australia's Health, op cit, p.87

[48] The Hon Nicola Roxon MP, Minister for Health and Aging, New Breast Cancer Nurses for Regional Australia,13 October 2008. http://www.health.gov.au/internet/ministers/publishing.nsf/Content/mr-yr08-nr-nr134.htm (Accessed 18 May 2009) The committee notes that the Prostate Cancer Foundation and the Cancer Council of Victoria already offer scholarships to encourage registered nurses to undertake a training course specialising in prostate cancer care.

[49] Andrology Australia, Prostate Enlargement or BPH, 2006 http://www.andrologyaustralia.org/pageContent.asp?pageCode=PROSENLARGE (accessed May 2009)

[50] Prof. J. Best, submission 30, p.1

[51] Prof. J. Best, committee transcript, 9 April 2009, p.53

Appendix B.

LaTrobe University Prostate Cancer Nursing Course.

The Prostate Care Nursing Program (PCNP), an educational collaboration between The Cancer Council Victoria and La Trobe University, has been running since 2001, based on the highly successful Breast Care Nurse program. The role of the 'Breast Care Nurse' is well established professionally following a national evaluation, establishment of competencies and accreditation, whereas the specialist role of the 'Prostate Care Nurse' is relatively new and evolving. Despite the increasing prevalence of prostate cancer in the Australian community, there is very little evidence of the role, scope or practice and function of the prostate care nurse.

The PCNP is the only specialised program of study in Australia which prepares registered nurses to care for men living with prostate cancer, and their families. A feature of this program is the flexible delivery format which enables nurses to study off campus, a particular advantage for rural and remote nurses. The unit covers key content in evidence-based prostate care, health promotion and health education; the provision of support to men and their families; along with the nature and type of therapies used in practice. The PCNP can be undertaken as a single unit over thirteen weeks or accredited towards a Graduate Diploma in Cancer Care or Urological and Continence Nursing.

Nurses receive a distance learning package comprised of a study guide, activities, assessment tasks, readings (via Web or CD ROM), and selected text books. Contact with lecturers and other students is through Web CT, a web based interface which gives each student an email address and the ability to easily chat with other students in the course. Study scholarships are generously provided through the Prostate Cancer Foundation of Australia. The program has two intakes each year, and 173 nurses from rural and metropolitan areas throughout Australia, including several students from New Zealand, have now completed the course.

Topics covered in the learning package are:

Session 1 Anatomy & Physiology of the Prostate and Related Structures

Session 2 Multidisciplinary Health Assessment

Session 3 Benign Prostate Disease

Session 4 Prostate Cancer

Session 5 Psychosocial Support Issues

Session 6 Treatment Options for Localised Prostate Cancer

Session 7 Diet and Complementary Therapies

Session 8 Treatment Options for Advanced Prostate Cancer

Session 9 Sexuality and Prostate Cancer

Session 10 Symptom Management in Advanced Prostate Cancer

Session 11 Palliative Care

Session 12 Prostate Nursing Care: Role Development and Support Services

Appendix C

ROLE OF THE PROSTATE CARE NURSE

Based on the description of the breast care nurse position a job description could be as follows.

Qualifications/experience:

- Registered nurse working in the area of urology, continence, men's health, community or oncology nursing
- Successful completion of the LaTrobe University Prostate Nursing Care unit or equivalent.

Essential characteristics/skills

- Commitment to providing and maintaining a quality service
- Advanced communication skills
- Advocacy skills
- Ability to develop, implement and evaluate prostate nursing care
- Ability to prepare and present clear verbal and written reports

Personal attributes

- Friendly manner
- Open communicative style
- Excellent listener
- Team worker

Aim

To use accurate and up to date knowledge as well as advanced communication skills to ensure that men who are diagnosed with prostate cancer receive individualised support and continuity of care from nurses and the multi-disciplinary team.

Position summary

- Provision of specialised information, counselling, advocacy and support regarding prostate cancer by personal visits after diagnosis, maintaining continuity of care for as long as the man and/or his family need it.
- Provision of the opportunity for men to access information and discuss any issues related to prostate cancer, including aspects of diagnosis, watchful waiting, treatment, recurrence and advanced disease.

- Effective liaison with the multi-disciplinary team throughout all stages of the patient's care and informing men of other support services available through various other agencies.
- Maintenance of the accredited Prostate Care Nurse status and, as part of the Prostate Care Support Team, abiding by the Code of Ethics and Philosophy of the service.
- Receive referrals from clinicians, hospital personnel, cancer information and support services, other prostate care nurses in hospitals and community agencies and, if required, coordinate prostate care support volunteers and patient to patient visits to hospital and home.
- Take a leadership position in establishing the role of the prostate care nurse in hospitals by providing information and resource materials to other nurses.
- Provision of support and debriefing sessions to other prostate care nurses.
- Presentation of discussion papers regarding the role and what it is trying to achieve to colleagues and at conferences.
- Participation in a minimum of 2 days or 12 hours per year of prostate cancer related education for prostate care nurses. A log book or journal must record your attendance at each of these sessions.

9 September, 2009