The Secretary,
Senate Community Affairs References Committee
Parliament House
Canberra ACT 2600

Dear Sir, Re: Inquiry into gynaecological cancer in Australia

I wish to make a submission for consideration of this inquiry, in view of my particular interest in this matter : as a physician with a background in cancer medicine I was asked to return to Sydney in 1985 to direct the development of palliative care services, especially through palliative medicine consultancy and training of registrars, in Royal Prince Alfred Hospital and Central Sydney. In 1991 I was appointed concurrently to do the same in Prince of Wales group of hospitals. Since leaving full time work in Royal Prince Alfred Hospital in January 2005 I have continued part time at Royal Hospital for Women, in view of my recognised subspecialty interest in palliative medicine (especially the clinical science related to the understanding and treatment of symptoms and approaches to decision-making in complex situations) and the field of gynaecological oncology. Therefore the matter of this timely and significant inquiry concerns me very much, and for this reason I request either an extension of time to make an adequate submission, or some other opportunity to discuss the issues. I have for the last three weeks been incapacitated by an accident from which I should make a full recovery, but which makes it difficult to do justice to the opportunity presented by your inquiry.

May I simply summarise the points I wish to highlight, knowing that you will receive excellent submissions from other persons and groups. I refer to the headings in your terms of reference.

a) I support the need for increased funding for research concerning the complex factors involved in causation, response and resistance to anti cancer treatments, processes of spread and progression , and mechanisms underlying symptoms, and tests suitable for screening.

In addition I note that hardly any systematic descriptive research is available concerning the morbidity experienced by women with gynaecological cancer in Australia throughout the course of their illness, whether eventually cured or not : morbidity related to period around diagnosis, associated with anticancer treatment, or continuing long after treatment has been completed (the experience of survivorship) : Australia-wide research in these dimensions of the illness experienced by women with gynaecological cancer would add substantially to understanding and provide a better basis for provision of care.

Much is known about many of these matters , excellent work is in progress in basic research, but much remains to be understood, for example, in my own field concerning the relationship of certain bowel symptoms (often dominant causes of distress) to ovarian cancer. Funding clearly needs to be more readily available.

b). Funding for "wider health support programs for women with gynaecological cancer" needs to take note of some of the particular problems associated with these illnesses, noting especially that the cancers and the anticancer treatments have the potential for serious effects on close relationships, because of the impact on many aspects of sexuality. Women are crucial in society, not only because of their intrinsic value as persons, but also especially with respect to their caring role and capacity to facilitate human connections…and this is threatened by cancers affecting women across a broad age span, such as breast and gynaecological cancers, but the added burden of threatened or impeded sexuality is a special feature of gynaecological cancer.
Research bearing on these social aspects needs to be strengthened, but existing knowledge is sufficient to indicate that far greater attention is needed as a routine aspect of anticancer therapy and surveillance, throughout the course of an illness which may go on for several years (more than 5) even in patients who will eventually die of the disease. Whatever information is available concerning the needs of the partners of patients with gynaecological cancer needs both collation and relevant action/funding .

In all such considerations the diversity of the trajectory experienced by patients needs to be kept in focus : some patients die within a few months of diagnosis, others have an event free life for years once the initial treatment is over (hopefully with little treatment related morbidity), other have a roller coaster ride with remissions and relapses –for years, and other are truly chronically ill for several years, with either smouldering symptomatic cancer slowly progressing or, less commonly, significant treatment related morbidity, paying a high price for probable cure, and others have a prolonged (months or a year or so) period of severe disability preceding death from the cancer. We do not appear to have adequate information concerning these profiles, and as mentioned, Australia wide research concerning morbidity patterns appears needed and feasible : readily available mortality figures are nowhere near enough.

Research concerning the adequacy of care, and the efficiency of the match beween needs and care is a major matter for consideration and funding, but I am sure others will deal with this.

The experience of illness is a complex aspect of the human condition, and I have given further consideration of this elsewhere (Lickiss JN The human experience of illness, in Walsh et al Palliative Medicine, Elsevier, in press 2006).

c) Others will address issues of the capability of services. I simply note that : issues relating to culture include not only ethnicity (profound in the case of gynaecological cancers) but also social factors/place of residence.
Cultural sensitivity is essential in Australian health services, but also includes understanding of the concerns of country patients : there may be a case for more on site visiting (by members of the treating centre) of country patients under

surveillance, but local factors will dictate the practicalities. Culture, in the broadest sense , influences not only presentation of symptoms, meaning of illness, understanding of information given, customs related to illness and death, but also decision making processes within famililies, and manner of receiving bad news and approaching death : education and clinical training for all staff concerned with patients (and families) needs to include such dimensions. Literature is extensive , and I have written briefly elsewhere (Lickiss, Med J Aust 2003 or 4).

Management of symptoms throughout the course of the narrative, whether the woman is curable or not, may require the availability of a palliative medicine specialist to assist colleagues, and psychological distress (of patient, partner and/or family) may be so complex that specialist assistance from a palliative medicine specialist is needed , for example when "bad news" has been communicated, family conflict is extreme concerning treatment decisions, or when patient is close to death.

Bereavement care requires focus also, but I will not attempt to deal with it in this submission, save to indicate that grieving associated with loss can occur at any point of the illness, and that bereavement care of partner and family should be in accord with established guidelines(eg NSW Health) and funding should be available to every Gynaecological Cancer Centre to ensure compliance.

Note that palliative medicine as a clinical science is not specified by the prognosis of the patient. USA has led the world in stressing that the principles of palliative care, especially good personal support (including support of family)and symptom relief should begin at the time of diagnosis (Institute of Medicine Report, Approaching Death 1997 and subsequent reports). This concept/directive does not necessarily mean that personnel of a specialist palliative care service should be routinely involved at time of diagnosis. It does mean that specialist level competence should be available if problems are severe at any stage of a cancer illness, at least by a consistent consultative arrangement.

There are few oncologists (surgical, medical or radiation) with any specialist training in palliative medicine : there could be advantage in the development of intensive training modules in palliative medicine in relation to gynaecological oncology for specialists in fields other than palliative medicine and for GPs wishing to enhance skills in that area. The efforts of Royal Hospital for Women ,Randwick in collaboration with Sydney Institute of Palliative Medicine in professional education in this field should be encouraged.

Funding of a major gynaecological cancer centre with a demonstrated commitment/tradition to professional training/ education in palliative medicine should be sufficient to ensure : Registrar position(or a Fellow) in Palliative Medicine and Continuing Care in Gynaecological Oncology, which could be a specialist training post for trainees of RACP in palliative medicine or oncology, or radiation oncologists (? surgeons): the post should involve commitment to assist country practitioners (specialists and GPs) , an educational role (medical students as well as staff of gynaecology units), and carry a research responsibility to investigate various aspects of outcomes of anti cancer treatment as well as profiles and mechanisms of symptoms. Supervision of the trainee would require part time consultant in palliative medicine and adequate library resources on site.

d) Mention has already been made of the need to enhance the knowledge and skills of the medical community with respect to palliative medicine in the contemporary understanding of that word. The Oxford Textbook of Palliative Medicine (3rd edition, ed by Hanks et al) gives an idea of the breadth of the field. Funding should be provided to develop educational initiatives, preferably with a clinical component, based on a National Centre in concert with specialist gynaecological cancer centres throughout Australia.
There is an obligation for making efforts to enhance the care of women also internationally, especially in our region, by stressing the necessity for good symptom relief and support in parallel with any efforts made to treat the cancer :there is no place now for the concept that pain relief (or aspects of palliative care)should only be considered when anticancer treatment has failed, but such attitudes persist in some areas and cause serious distress. Australia has an obligation for leadership in this matter, in view of the overall excellent of gynaecological oncology in Australia.

e) I leave to others to discuss the issues relating to Cancer Australia, save to stress that gynaecological cancers are common, cause particular problems, and need far more focus nationally, and that the care of women with gynaecological cancers involves not only treatment of cancer, but treatment of symptoms and also psychological sequelae, both often overlooked in the glare of anti cancer treatments , even in the best centres, and in cancer survivors ..And we do not have adequate knowledge of how things are , and we should.

I would be pleased to expand on or clarify any of the points raised, and apologise for one handed amateur typing, my best effort in my present circumstances. I recognise that the submission is not adequately referenced not entirely logical in sequence, but having decided to submit some points rather than just a letter of intent, I hope that the matters raised will at least provide a basis for further discussion.

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