SUBMISSION TO THE

SENATE ENQUIRY INTO SERVICES AND TREATMENT OPTIONS FOR PERSONS WITH CANCER

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Please Note: Should the Committee be interested I am happy to provide further detail on these issues in writing or in person.

EXECUTIVE SUMMARY

1. With the benefit of international and national research, cancer treatment in Australia has improved significantly over the last 30 years, yet access to genuine multi-disciplinary care is still unavailable for the majority of patients.

2. Apart from management of some types of cancer (breast & head and neck cancers) and with the exception of the Peter MacCallum Clinic in Melbourne there is little, if any, properly organised and funded multi-disciplinary care in Australia. What has started to be achieved with treatment of breast cancer needs to be applied to other cancers. Multi-disciplinary care in comprehensive cancer centres that are properly funded can address many problems more effectively than the current fragmented approach, including services for regional Australia. They would also facilitate more support for clinical trials.

3. There are too many organisations trying to do the same thing – many of whom receive government funding to some degree. There is room for better organisation and efficiency.

4. There is resistance to change within the medical profession some of which may relate to a lack of financial incentive. A credentialing system needs to be introduced that assesses a cancer specialist's abilities and experience in context of treating different types of cancers. The Australian Cancer Network is developing a strategy but there are no resources to really make it work.

5. An accreditation system needs to be developed that applies standards of care within whatever setting cancer is treated. Again, the Australian Cancer Network is tackling this issue but with limited resources. Strategy documents & guidelines are useless unless they are properly applied and the results measured. The National Breast Cancer Centre has completed a study with recommendations for accreditation of breast cancer treatment services. Reviewing how this work in other countries has assisted in this process.

6. Better co-ordination of a cancer patient's 'journey' is important as well as access to psycho-social support. Not every patient will require such support. National guidelines for psycho-social have been developed but, apart from some breast cancer centres, there are no resources in the system to really apply them

7. Government and non government organisations need to collaborate on providing better, objective information about different types of unorthodox or unproven cancer therapies and the products promoted in this sector. Multi-disciplinary centres can provide a threshold for the controlled introduction of complementary therapies that, over time, can be scientifically assessed.

These already exist in other countries and one centre provides such a service within a teaching hospital in Perth but without budgetary support from within the health care system.

8. In the United Kingdom The Macmillan Cancer Support Association (one of the most vigorous and most interactive non government organisations that is highly respected by mainstream health professionals and complementary therapists has a full time doctor on the staff responsible for Complementary Cancer Therapies (Dr Michelle Kohn). The Chief Medical Officer is Dr Jane Maher a Medical Oncologist who has set up a Complementary Therapy Unit within the Mt Vernon Hospital in North London which is a major cancer treatment centre. All the cancer specialists in that hospital and also within the regional health authority (private as well) refer patients who are interested in complementary therapies to that unit. This demonstrates how a medically conservative organisation such as MacMillan has embraced complementary therapy within the framework of orthodox medicine as a result of patient demand.

9. The report “OPTIMISING CANCER CARE IN AUSTRALIA” published in February 2003 (ISBN 1 876992 01 8) is recommended reading for the Committee.

INTRODUCTION

This submission is made by Clive Deverall, a cancer patient with non-Hodgkin's Lymphoma who has worked in the cancer field for more than 25 years as Director of the Cancer Council of WA 1977-2000 and as a member of the Board of the Cancer Council Australia for an equivalent period. I am currently a consumer representative on the Commonwealth Department of Health and Ageing's National Cancer Strategy Group and also on the Research Committee of the National Health and Medical Research Council (NHMRC) in the same capacity.

ADDRESSING THE TERMS OF REFERENCE

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.

Since the early 1980s there has been growing evidence of the benefits of multi-disciplinary cancer treatment. Numerous cancer specialists who trained overseas and returned to work in Australia spoke in glowing terms of comprehensive cancer centres that practised multi-disciplinary care such as the M.D. Anderson Centre in Houston, Texas, the Sloane Kettering Centre in New York, the Mayo Clinic, the Royal Marsden Hospital in London etc, etc. Many of these specialists made efforts to introduce multi-disciplinary care in their own hospitals but, over time, were frustrated by the historical problems of lack of interest by their peers, professional jealousies and not enough resources. Inevitably, most of those cancer specialists gave up and concentrated on developing their own public and private practices to the best of their abilities. A few very enthusiastic ones managed to plough on and make a significant difference in their own hospitals but continued to find it difficult to really provide real multi-disciplinary care due to the allocation of resources within their hospitals. As we went into the nineties with more evidence but still little progress, some oncologists even took up defensive positions stating that no real evidence existed to support multi-disciplinary care or comprehensive cancer centres and that they practised multi-disciplinary care by discussion with fellow oncologists about problems they may have encountered with individual patients (this is usually a fairly informal exchange of information on a collegial basis in a public or private setting – a long way from well organised, comprehensive, multi-disciplinary care). With the exception of the Peter MacCallum Cancer Clinic there is no comprehensive cancer centre in Australia though some hospitals claim to have comprehensive cancer services. Some specialities such as breast cancer and head and neck cancer have developed multi-disciplinary care but a minority of cancer patients ever have the opportunity of receiving it. Further comment will be made in (a) (v).

(ii) The role and desirability of a case manager/coordinator to assist patients

Some patients who are diagnosed with an early stage cancer are treated and, most often require limited ongoing support within the health care system. Others, with more advanced disease are often faced with a long, complex “cancer journey”. A proportion of these patients will be referred, in the first instance, by their GP to a private cancer specialist. Many of these patients are referred on to a startling number of other medical specialists for radiology, pathology, endocrinology, radiotherapy etc. They remain ‘the property’ of the original consultant and, especially if treated in a private clinic/hospital, never have access to anyone else’s professional advice. A few seek second opinions but most rely heavily on the specialist to whom they were first referred. This also happens in public hospitals, including teaching hospitals, where there is no clear pathway of co-ordinated care. This is recognised as “the patient ownership issue” but has never been tackled as it is such a complex and sensitive medico-political issue. It relates to other diseases as well as cancer. Many patients will never be cured of their disease but will survive (perhaps for many years) on maintenance therapy or be part of long term clinical trials which they have been persuaded to participate in by their own specialist – most often, without access to other advice. It is in this scenario, that is common throughout Australia, that case managers/coordinators could play a very effective, efficient and probably cost saving role. Australia faces an increasing incidence of cancer as the population ages. With anticipated improvements in treatment, including earlier diagnosis, there will be an enormous increase in the numbers of patients who will survive with their cancer and probably die, ultimately, of other diseases of old age. This is the same pattern throughout the western world. Case managers would be the most effective and economic method of supporting this population of patients as well as those who are cured following their treatment.

(iii) Differing models and best practice for addressing psycho-social factors

The National Cancer Strategy Group in its report Priorities for Action in Cancer Control 2001-2003 (Publication number 2979) identified and provided scientific verification of the benefit to cancer patients in receiving support from psychologists in cancer centres. The report went further with this particular recommendation by stating that such a service could also be provided by other suitably trained/qualified health professionals. Unfortunately, there is hardly a public hospital in Australia, including teaching hospitals, which provide line items in their budgets for psycho-social support for cancer patients. The non government sector, in the form of the State and Territory Cancer Councils and other organisations, do their best to provide this type of support but it is not co-ordinated within the health system and most importantly is not yet part of an organised multi-disciplinary approach.

(iv) Treatment options for regional Australia and Indigenous Australians

This is a patchwork quilt reflecting the problems of providing specialised services across wide geographical areas. Some services have a reasonable record and those are usually linked to a major hospital in a capital city which provides a visiting outreach service. They are also usually staffed by ‘enthusiasts’ who are happy to tackle the challenges involved. The solution is development of resourced comprehensive cancer centres which supervise regional outreach services.

In terms of providing services for Indigenous Australians; it is accepted that deaths from cancer in this community are low as deaths from other causes, often earlier in life, is a dominating factor. The Commonwealth Department of Health and Ageing (DoHA) has also encouraged the setting up of better palliative care services for Indigenous Australians and the NHMRC continues to oversee research activity in this, difficult to service, sector. Cancer of the cervix is a common cancer in females and finding and treating this easily treated cancer early is frustrated by the social problems in delivery of Pap smear services. Attempts continue to be made by government and non government services to overcome the problems.

(v) Current barriers to the implementation of best practice in the above fields

The major barriers are:

- **Lack of development of multi-disciplinary care**
- **Lack of national standards and a system of accreditation of cancer treatment facilities**
- **Lack of a system to credential individuals who treat cancer.**

These three issues have been on several agendas managed by The Clinical Oncological Society of Australia (COSA); The Cancer Council Australia (TCCA) and the Australian Cancer Network (ACN) and possibly the National Cancer Control Initiative (NCCI). All these are in the non government sector. Only recently has the DoHA’s National Cancer Strategy Group started to promote the National Service Improvement Framework for Cancer which relates, in part, to these three issues. However, there is reluctance by the various Colleges and Specialist Groups (surgeons, physicians, urologists, radiotherapists, and pathologists etc) to proceed with any enthusiasm or speed. Many individuals would prefer that the issues disappear. There will be no progress unless there is leadership in the sector together with financial incentive and/or enforcement. It is imperative that it covers the private as well as the public sector as an increasing number of patients are being treated privately or accessing both sectors.

Both accreditation and credentialing are essential building blocks for the delivery of sustained multi-disciplinary care. Accreditation should cover the public and private sectors – especially the latter where we are increasingly seeing extensive new (so called and self christened) cancer treatment centres being built which do not embrace the fundamentals to deliver multi-disciplinary care. To my knowledge there is not one hospital based cancer registry in the private sector (with the exception of the Peter MacCallum Clinic). This means each patient's treatment is never comprehensively recorded or measured in terms of length of survival and quality of life which is essential information for the delivery of multi-disciplinary care. In the public sector in most states the matter of hospital based registries is erratically managed. In Western Australia the public hospitals have ended up with different types of computerised registries in each hospital, none of which can 'talk' to the other. The funds were provided by the State government but in an unsupervised manner. Hospital based cancer registries are essential to monitoring what happens to patients (why continue treating patients with a particular protocol if you know it does not improve survival and/or the side effects are overwhelming?). Hospital based registries are also an essential building block for sustained accreditation and credentialing.

Credentialing of individuals who treat cancer is also very important and is common practice in the United States. Credentialing relates to an individual doctor's experience in treating a particular type of cancer and should relate to how and who a GP refers a patient. Too much GP referral at present is based on who the GP knows or has heard of and not on solid data that is made available by a Health Department or another independent, authorised organisation.

b. How less conventional and complementary cancer treatments can be assessed and judged with particular reference to:

(i) The extent to which less conventional and complementary treatments are researched, or are supported by research.

HISTORY AND BACKGROUND

Even fifteen years ago there were complementary treatments described by some doctors in mainstream medicine as unorthodox and/or unproven and therefore of no benefit to patients. Over time and partly due to the efforts of palliative care services, some of these treatments have been adopted, especially in palliative care units in government and non government hospitals – in particular in non government owned hospice units. These include reiki, various massage techniques, meditation, sequential muscle relaxation etc. No specific research was conducted in order for this to happen nationally but it became more and more evident from clinical observation that none of these therapies did any harm but actually helped the patient play a more positive part in their own treatment. However, the majority of oncologists, especially in teaching hospitals, remain unconvinced and continue to treat virtually all non-orthodox therapies with scepticism and some disdain. This is, to a certain extent, a generational problem. No amount of effort is going to persuade the older clinicians to be more moderate.

THE CURRENT SITUATION

Younger specialists will hopefully be more relaxed and open minded in their attitudes and perhaps the environments in which they work could become less austere and more accommodating leading to greater comfort and satisfaction for patients and their carers. Encouraging the development of comprehensive cancer centres which provide multi-disciplinary care could enable patients to have access to a range of complementary therapies without any threat to the integrity of their treatment. Within such an environment a wide range of information can be made available about different types of alternative, complementary or unproven therapies which will enable patients and their carers to come to informed decisions. State and Territory Cancer Councils would work very well in such a framework. There are precedents for complementary therapies to interact with orthodox oncology in public hospitals in Australia, the UK and USA.

Currently, too many cancer patients receive derogatory remarks about any treatment that is not specifically prescribed by the oncologist. This does not encourage patients to inform their specialist what complementary therapy they may also be using which could compromise their mainstream treatment.

At present there is little funding available for research into less conventional therapies. The NHMRC has however recently quarantined some funds for research in this sector. This sphere of research is, at present, unlikely to attract many experienced researchers as it would not be complementary to their research or academic records. In the USA a very significant effort is being made with research primarily funded by government. Translating the outcomes of the American research effort into easily understood information for patients in Australia might be a positive and inexpensive intervention – at least as a first step. Gathering information about the different therapies (especially the products that are available in tablet, liquid and injection form) from other countries and, perhaps the manufacturers or distributors as well, would also be helpful. Quality control, relative to some of these products, many of which are sold directly to patients, is of concern. In March 2004 the NH&MRC were involved in a “Review of Complementary Medicines in Australia” (contact Suzanne Northcott – Executive Director, Centre for Research M’ment & Policy – 02 6289 9111).

(ii) The efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary thereapies

The efficacy of less conventional approaches would also be difficult to demonstrate either as a primary treatment and probably even more in terms of an adjuvant effect. Gaining ethical approval for such research could be problematical. Clinical trials have been mentioned but ethical and funding issues are barriers at this time. Only at the end of 2004, following relentless coverage by Channel Nine’s A Current Affair, did the Federal Minister for Health instruct the NHMRC to conduct an investigation into the unproven cancer therapy provided by Dr John Holt in Perth. This treatment (originally known as Tronado or VHF Microwave Therapy) has been available since 1973. Patients receiving the treatment receive some Medicare rebates but have to cover the gap themselves. In context of orthodox cancer treatment there is no published evidence anywhere that would convince the majority of doctors to refer patients to Dr Holt. The Cancer Council Western Australia conducted a clinical trial in co-operation with Dr Holt over 8 years in the 1980s but the results showed no therapeutic benefit either curatively or palliatively. Yet, hundreds of patients a year continue to be treated by Dr Holt based on word of mouth and/or media recommendation.

(iii) the legitimate role of government in the field of less conventional cancer treatment

Government could play a more positive role in order to clarify what is happening in this well patronised sector. Such initiatives that need to be taken include:

- Encouraging the provision of objective, up-to-date information in order that patients and carers can make informed decisions.

- Regular publication of a list of products in this sector that are sold in any form that are taken orally (or in any other manner) by patients with any information that relates to contents, known side effects etc. It is suspected that some products can act as tumour promoters or cause toxic reactions. This is of particular importance when individuals may work on the principle that “if something is good for you, more could be better”.

- Governments could encourage the presence of more cancer consumers in the planning and overview of services as they are the ones who are aware of the issues and also what alternative or complementary therapies are in the market place which has been significantly increased by the internet.

CONCLUSIONS AND SUMMARY

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problems more effectively than the current fragmented approach, including services for regional Australia. They would also facilitate more support for clinical trials.

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