



SUBMISSION TO THE
SENATE CANCER INQUIRY

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14 March 2005

Cancer Voices NSW is the peak coalition for NSW cancer support and advocacy groups. It provides a voice for the 4,000 members of those groups and works to improve the cancer journey for people affected by cancer. We are interested in the areas of prevention, diagnosis, information, treatment, research, support and care. Similar Cancer Voices are being established in all Australian states and territories.

Introduction

Cancer Voices is the peak coalition for cancer support and advocacy groups in NSW. We directly represent groups whose membership totals over 4,000 and work for the benefit of all Australians affected by cancer.

We are delighted to provide a submission to the Cancer Inquiry. We suggest the outcomes of this Inquiry be presented for action both to Government and to the newly formed national cancer organisation, Cancer Australia. These sorts of matters were raised by the Optimising Cancer Care in Australia (OCCA) report (2002), a major recommendation being that a national cancer umbrella body be established. Due partly to our substantial contribution to that report, it is very patient-focused and we commend it to the Senate Cancer Inquiry.

Cancer is the leading cause of death for Australians.

While it is frequently thought of a disease of the old, it is the most common cause of years of life lost in adults 25-64 years old – their most productive years economically and socially. Government spending on cancer is minimal compared to the overall impact on Australia and Australians: cancer accounts for only 6% of the health expenditure and 7% of the PBS budget.

Cancer is traditionally treated by passing the patient from specialists to specialist. Only a few cancer patients benefit from a multidisciplinary approach, or indeed experience a co-ordinated treatment journey. We see this Inquiry as raising the awareness of the need to do both across all treatment centres, encouraging more cancer clinicians to treat patients in such centres, wherever this is at all possible.

We are pleased to address the Terms of Reference as follows.

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.

Cancer Voices and its member groups, especially the Breast Cancer Action Group NSW, have long supported the introduction of the multidisciplinary care (MDC) approach in the treatment of all patients with cancer. While recognising this is not always practical, especially in rural and remote Australia, we commend the use of technology to overcome the tyranny of distance – via video conferencing with larger centres. Expensive, but cost efficient in terms of lives saved and use of most appropriate treatment.

We wish to add:

- MDC should be offered to all cancer patients, regardless of the stage of disease progression - often the "simple cases" are not processed by the MDC team, with unfortunate results (examples provided)
- MDC should be made available to Australians whose disease has progressed beyond the primary tumour, has recurred or metastasised. Our members advise this is not often the case.

We commend the work of the National Breast Cancer Centre in undertaking translational research into the efficacy, value and practicality of the MDC approach, and for including the consumer perspective throughout this process.

The *Clinical Service Framework for Optimising Cancer Care in NSW* (NSW Health 2003) set a series of standards which should be met by Area Cancer Services. There are four standards to achieve compliance for MDC practice under Standard 5 of the Framework (page 19).

Recommendation: That the Cancer Inquiry recommend that broad principles of MDC be adopted for the treatment of all cancers.

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

Cancer consumers frequently report on the ad hoc, "silo" nature of cancer care in Australia. This situation was clearly identified by the BCAG NSW study *"Falling Between the Stools? – A Survey of Women's Experiences of Breast Cancer Services in NSW"* (Nov 2001) ISBN 186507 071 8, and the OCCA report. This has been the experience of most of us, and was the experience of NSW Minister Frank Sartor, which led to enhanced cancer funding via the Cancer Institute NSW and now of Senator Peter Cook. Navigating the shoals of the cancer treatment journey is well recognised as one of the most difficult aspects following the grim news of diagnosis.

Cancer has traditionally been treated through a number of distinct specialties, particularly by surgeons, radiation oncologists, medical oncologists, haematologists, and palliative care specialists. Most of the practitioners operate and think as sole traders, even those who occasionally, or even regularly, meet for MDC discussions of patient's profiles.

The *Clinical Service Framework for Optimising Cancer Care in NSW* (NSW Health 2003) includes Standard 3.2 relating to care co-ordinators and case managers.

Recommendation: The Inquiry recommend that all Australian cancer services make provision for care co-ordinators. And that cancer curricula and training emphasise the necessity of co-ordinators/ case managers – for the benefit of both patient and specialist clinicians. Co-ordinated planning and information will make a patient feel much more on top of what is happening to him or her – benefiting from the value of empowerment for recovery. There is some evidence which confirms that patients who feel confident and in control will have better outcomes.

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

Recommendation: That the NHMRC Guidelines for Psychosocial Care be implemented at all cancer services and be taught during medical and nursing training.

We wish to draw attention to the important role of cancer support groups for many people during their cancer journey. The government's 2004 election commitment of \$2m over four years to encourage support group networks, requires \$500,000 to be allocated before 31 June 2005, representing the first tranche. The policy favours tumour stream cancer support groups, with little overt encouragement to those groups attended by the majority of cancer patients who seek this kind of psycho-social help. Recent studies have shown that both types are equally beneficial. In many cases tumour specific support groups simply cannot be

supported by demographics – if you live in the country, or in part of the metro spread, there is not option.

Recommendation: That the Inquiry recommend to government that this funding be allocated across all cancer support groups and their networks, at local, state and national levels.

(ii) *Current barriers to implementation of best practice.*

- Lack of funding to develop and publish national Guidelines
- Lack of funding to develop and publish guidelines for those cancers which currently do not have them, and for updates of earlier Guidelines.
- Need for Guidelines to be adopted and acted upon by all clinicians providing cancer services.
- State health services still do not see cancer as a priority
- Lack of an accreditation system, whereby only those cancer services which implement best practice receive full allocation of funding.
- Lack of an accreditation system for individual cancer specialists
- Ad hoc inclusion of representative cancer consumers in policy development and decision-making

Recommendation:

- Government to support development and implementation of Guidelines and accreditation systems.
- Government legislate that representative cancer consumers be invited to participate at all levels of decision-making.

(a) *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.*
- (ii) *The efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies*
- (iii) *The legitimate role of government in the field of less conventional cancer treatment*

General comment:

We understand that approx 67% of cancer patients use less conventional and complementary treatments during their cancer experience, and that this is at a higher rate than use by other health consumers. This may be explained by the fact that cancer is often incurable and the knowledge about its causes, progression and optimum treatment is less certain compared to other major diseases.

Complementary therapies tend to fall into the “do no harm” category, can be used at the same time as orthodox treatments without impacting adversely on them and anecdotally often appear to help the cancer patient a great deal. These include meditation, relaxation, visualization, some nutritional supplements, among others.

Some cancer patients use alternative therapies instead of orthodox, others use complementary therapies alongside orthodox. Some tell their clinicians, and some do not. Some of the therapies used could impact negatively on the orthodox treatments. eg on the efficacy of chemotherapy. A great deal of money is spent on such therapies, often spent in desperation, by those who can ill afford to do so. Some such therapies also sold by people who prey on the fear and uncertainties of very sick or scared people.

There is little or no imperative for commercially supported research, as the therapies cannot on the whole be "owned". On the other hand there is a large market for them, so another research model should be tried, different to the pharmaceutical study model.

We believe it should be a government responsibility to fund or encourage this type of research. This may be in the form of incentives, perhaps development of a template for less rigorous requirements for research than for orthodox drugs, but requiring Therapeutic Goods Administration (TGA) approval before these products are marketable. A proportion of the market price could be returned to support this research.

At the time of writing we hear that the Government's response to the report by the Expert Committee on Complementary Medicines in the Health System has been released – this may have useful bearing on discussion about assessment of, and research into, the efficacy of these therapies.

Australians need a central organisation – perhaps the new *Cancer Australia* – to take on the responsibility of providing to cancer patients, their carers, their advisers, the media, and the community, as much info as can be reliably provided about all such therapies. The process could be via the TGA, which has a Complementary Medicines Evaluation Committee – however, very little accessible cancer related work appears to have come out of this group to date. Some role for government is very legitimate – it is essential to change the present situation.

Recommendation:

The Inquiry make a recommendation to Government that funds be allocated or re-directed to ensure there is a central information authority for cancer, considering the particular uncertainties that surround this disease, its risks and its therapies. This should be based on a process of investigation into efficacy, with reference to international sources, and TGA approval.

The writer is a ten year cancer survivor and is currently living well with advanced breast cancer. The Executive Committee of Cancer Voices NSW would be pleased to speak at the Senate Cancer Inquiry hearings if you would like to pursue these ideas further.

Yours sincerely

SALLY CROSSING
Chair

14 March 2005