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Submission by Brain Tumour Australia Inc

Senate Community Affairs Committee

Inquiry into services and treatment options for persons with cancer

Summary: Tumours of the brain and central nervous system (CNS) can have a devastating effect on the patient, their family, and carers. The prognosis for a person with a primary, malignant tumour is poor. The range and effectiveness of available treatments is minimal. There is insufficient expertise and specialisation. Much more could be done in the areas of research, clinical practice, and support for patients and carers.

Background: In 2001 (latest available statistics) 1421 Australians were diagnosed with a malignant primary tumour in the brain or central nervous system and 1077 people died from these tumours.

More men (786) than women (562) were diagnosed with brain tumours.

Brain tumours affect people of all ages - from babies under twelve months of age to the very elderly. In contrast, no female under the age of 20 years was diagnosed with breast cancer in the same reporting period, and no man under 35 years was diagnosed with prostate cancer.

In the report *"Cancer in Australia 2001"* the following comment appears: "Cancer of the brain and nervous system is responsible for the fourth highest number of person-years of life lost (16,968). This contrasts with its ranking as the fourteenth most common cancer (1,421 new cases diagnosed in 2001). Further, the ratio of person-years of life lost to new cases for cancer of the brain and nervous system (11.9) is much higher than that for lung cancer (5.4), breast (2.4) or colorectal cancer (2.3). This is a direct result of the relatively large number of younger people dying from cancer of the brain and nervous system." (Section 2, page 7.)

Brain tumours are now responsible for slightly more deaths (40) of children under 15 years, than all leukaemias (36).

In 2001 twice as many people died from malignant primary brain tumours (1077) than from mesothelioma (519).

(Source: Australian Institute of Health and Welfare (AIHW) & Australasian Association of Cancer Registries (AACR) 2004. Cancer in Australia 2001. AIHW cat. no. CAN 23. Canberra: AIHW (Cancer Series no. 28).Tables 34, 35, 42, 46, 50.)

Many other people experience brain tumours which metastasize from a cancer located elsewhere in the body - estimated to be about 11,200 people per year (see footnote 1), and another estimated 1,400 people experience so-called benign brain tumours which can be debilitating and life-threatening (see footnote 2). Statistics for benign brain tumours are not collected at a national level, even though they may result in the patient's death.

The diagnosis of a brain tumour can have a devastating effect on the patient, family and carer, because the brain controls all physical and mental functions of a person's body.

Standard therapy of neurosurgery, radiation therapy and chemotherapy, has remained virtually unchanged for the past 30 years, except for the recent welcome development of temozolomide as a reasonably tolerable therapy for *glioblastoma multiforme* and *anaplastic astrocytoma* tumours, which are the most common of the primary malignant tumours.

These tumours generally carry a poor prognosis, the estimated survival period for a primary glioma tumour being eleven months. Five-year relative survival after diagnosis of a brain cancer in Australia is currently 24% and has not improved since the early 1980s, unlike the improvement in survival rates experienced by most other types of cancer.

In all three arms of standard treatment there is insufficient volume of numbers for widespread specialist expertise to develop. There are very few neurosurgeons and oncologists in Australia who specialise in the treatment of brain tumours and there is very little inter-connection between the three clinical treatment areas. Less than 5% of the workload of a typical neurosurgeon would be related to brain tumours. Most medical oncologists spend a majority of their professional time on the major cancers: breast, lung, colorectal and prostate cancer. The average General Practitioner might only encounter two or three brain tumour patients in their entire career.

The cause of primary brain tumours is unknown and consequently there are no known preventative measures that can be undertaken. Mass community screening for the early detection and treatment of brain tumours is impractical.

The medical treatment of brain tumours carries a unique set of challenges, including protection of the brain by the blood-brain barrier and the rigidity of the skull in encompassing the brain when swelling occurs through surgery, radiation therapy or tumour growth. There is very little original research about brain tumours undertaken in Australia and only a small number of clinical trials. Participation in multi-centre and international clinical trials is infrequent. There are no agreed clinical practice guidelines. There are only seven brain tumour-specific patient support groups in three States of Australia.

Terms of reference

The delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:

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

Comment: This would be very desirable for the treatment of brain tumours. The neurosurgeons who treat brain tumours have more multi-disciplinary involvement with their rehabilitation colleagues who are looking after patients suffering from an acquired brain injury (ABI), than they do with those who look after brain tumour patients. The interaction between neurosurgeons and radiation oncologists is usually perfunctory and infrequent because this is the only area of their work where neurosurgeons have reason to have contact with radiation oncologists. Greater inter-connection between radiation oncologists and medical oncologists is developing, principally because of the recent discovery of the efficacy of concomitant radiation therapy and chemotherapy. Because they are at different ends of the treatment path there is less frequent contact between neurosurgeons and medical oncologists, however, the recent emergence of chemotherapy-impregnated wafers (Gliadel) for insertion in the cavity after neurosurgery requires the neurosurgeon to develop some knowledge about neuro-oncology.

the role and desirability of a case manager/case co-ordinator to assist patients and/or their primary care givers,

Comment: This is very much needed for brain tumour patients, family and carers. The position has also been described as a "system navigator". The brain tumour journey has been likened to a "roller coaster ride" with a series of often terrifying ups and downs. Challenges can arise when the patient is moving between the three separate treatment arms and it is often difficult to contact someone who is familiar with the patient's situation and who can offer advice for a problem which is not necessarily in the emergency category. The co-ordinator could also smooth the way when a patient is transferring between the three arms and could offer a much welcome form of continuity and stability for patients and carers who have only limited contact with others in a similar situation. If it was thought that the numbers did not warrant a specific brain tumour case manager in some treatment facilities there may be value in a dedicated staff member to assist those with the less common or "minority" cancers. Pancreatic cancer is another disease similar to brain tumours in its incidence, mortality and prognosis.

differing models and best practice for addressing psycho/social factors in patient care,

Comment: We are aware of the useful psychosocial general guidelines for the treatment of people with cancer (available on-line at: http://www.nhmrc.gov.au/publications/pdf/cp90.pdf). However, because of the location of the person's tumour *in the brain*, brain tumour patients can experience unique site-related problems which may require specific attention. For example, people who received full-brain radiation therapy at a younger age and adult long-term

survivors may experience significant cognitive and personality-related deficits some years later, for which they need specifically-targeted help.

Associate Professor David Andrewes of the Psychology Department at the University of Melbourne has found in his research that brain tumour patients undergoing neurosurgery are rated by their partners as having significant emotional and social problems compared to a control group of patients which included patients with cancer to non-brain areas and other neurological patients. There were high levels of anger, depression, fatigue, indifference, maladaptive and inappropriate behaviour. It is the malignant tumour patients who show the most problems and these levels were also far in excess of levels reported for stroke and multiple sclerosis patients. (Source: Journal of Clinical Neuroscience (2003) 10 (4), 428-433.)

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

Comment: The publication *"Cancer in Australia 2001"* contains this observation: "In Very Remote Areas, age-standardised death rates for colorectal and brain cancers and leukaemias were all significantly below the national average, and the lung cancer death rate was significantly above the national average." We are unaware of why this might be the case for brain tumours. Indigenous people represent 45% of the total population in very remote areas. (Report, page 42.)

In many instances brain tumour patients from remote areas will have their craniotomy or biopsy in a major treatment centre and return to their usual residential location after recovery. They may also travel to the same or a different treatment centre for radiation therapy which typically takes six weeks. Brain tumour patients in some areas have been severely inconvenienced by a need to travel to alternative radiation treatment centres because of an inability to obtain quick access to local facilities.

Oral chemotherapy such as temozolomide can be administered on an outpatients basis. MRI and CT scans are frequently required by brain tumour patients, to check for tumour growth, particularly after an adverse event or during hospitalisation, and we acknowledge that the number of MRI facilities has increased in recent years, although we have heard anecdotal reports of some difficulties in non-metropolitan areas of Queensland. There is also the issue of the lack of "open MRIs", which are useful for patients who are extremely uncomfortable in the traditional enclosed MRI machine.

current barriers to the implementation of best practice in the above fields; and

Comment: Identifiable barriers include: Paucity of specialist resources, both human and material, which are usually concentrated in metropolitan areas; an absence of agreed clinical practice guidelines; a small number of clinical trials, low participation rates, and low involvement in international, multi-centre trials; few private or publicly-funded brain tumour-specific research projects.

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

the extent to which less conventional and complementary treatments are researched, or are supported by research,

Comment: We understand "less conventional" to refer to those treatments outside the parameters of "standard therapy" and "complementary" to refer to those treatments that are *in addition to or supportive of* standard or less conventional treatments, not "alternative treatments", which we understand to refer to those treatments undertaken instead of standard or less conventional treatments.

Less conventional: For the brain tumour patient, particularly the patient with a malignant primary brain tumour, access to a new therapy which has shown promise at a Phase II clinical trial level represents the chance to extend their survival during which they may benefit from access to other treatments which may prove beneficial. Unlike many other cancer patients, most brain tumour patients do not have an extended period of time, and the possibility of periods of remission, in which they can wait for the conclusion and publication of the results of a double-blind Phase III trial for a promising new therapy.

Brain tumour-specific research needs to be undertaken urgently so that new therapies can be quickly assessed and either pursued or discarded. This applies particularly to new chemotherapy agents which have proved efficacious for one cancer and are being researched for others, including brain tumours. Recent examples include Iressa and Gleevec.

the efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies, and

Comment: An example of a less conventional and a possible adjuvant/complementary treatment (but not common or extensively known in Australia) for brain tumours would be the use of Clomipramine (Anafranil) – a heterocyclic drug used for over 35 years to treat obsessive/compulsive conditions and depression. A research study of the possible anti-tumour effects of Clomipramine has been initiated in the UK by Kings College Hospital and Professor Geoffrey Pilkington, Professor of Cellular and Molecular Neuro-oncolgy, University of Portsmouth. It is known that some Australia patients, with the assistance of their oncologist or GP, have been following the recommended UK protocol for this study.

A range of immune boosting and supportive supplements, including Chinese herbal treatments, are used by some brain tumour patients as adjuvant/complementary treatments..

Two sources of information about these approaches are the book "Surviving Terminal Cancer" by Ben Williams who himself has a malignant brain tumour and has also experimented with different chemotherapy regimens, and nutritionist Dr Jeanne Wallace of the USA who has specialised in nutrition and dietary plans for brain tumour patients.

Two Australian carers of spouses who each have a malignant primary brain tumour have given permission for their name and contact details to be forwarded to the Committee, should you wish to explore this issue further with them. They have each

researched the area of complementary and adjuvant treatments for brain tumour patients in Australia and overseas and are both associated with Brain Tumour Australia Inc. They are:

Mr Ross Symons, 22 Antibes St, Mentone, Vic 3194, Phone 03 95875777 (h) and 0419 312 006 (Mobile); and

Ms Uschi Fitzpatrick, 6 Waratah Road, Palm Beach NSW 2108. Phone 02 9974 5307.

Similarly, Ms Kaye Duffy of 1/104 Memorial Drive, Bar Beach, NSW, 2300 has offered herself as a point of reference for the large percentage of people surviving with benign brain tumours.

the legitimate role of government in the field of less conventional cancer treatment.

Comment: If "less conventional" is interpreted as meaning "promising and soundly-based but not yet accepted as standard therapy", Brain Tumour Australia believes that the government should expedite the approval and subsidisation processes for access by brain tumour patients to these therapies. It is possible that some of these therapies, such as that currently being trialled in the UK regarding Clomipramine, may not be attractive to pharmaceutical companies because of patent and profitability considerations. Governments may need to step in and provide funding for this kind of research.

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Footnote 1. "In the US there are about 150,000 people diagnosed with a metastatic BT each year" - Source: American Brain Tumor Association brochure. "In the US there are an estimated 18,400 new cases of primary malignant brain and central nervous system tumors expected to be diagnosed in 2004. " (Source: www.cbtrus.org/factsheet/factsheet.html) This represents a ratio of about 8:1, suggesting that about 11,200 people (1400 x 8) will be diagnosed with metastatic brain tumours in Australia each year.

Footnote 2: Extrapolation from United States data suggests that there are almost as many Australians diagnosed with benign brain tumours, as those with a primary, malignant brain tumour.