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The Secretary
Senate Community Affairs References Committee
Suite S1 59
Parliament House
Canberra ACT 2600

Dear Secretary

INQUIRY INTO AGED CARE

I write with particular reference to Terms of Reference (c):

(c) the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements;

I am Chair of Brain Tumour Australia Inc (BTA), a non-profit group for people with an interest in brain tumours. BTA was established at a Workshop of patients, carers and health professionals, held in Sydney in July 2003 which was attended by 57 people from around Australia. Regional meetings were later held in Melbourne (September) and Brisbane (November). A second Workshop was held during 5-6 June 2004 which attracted 84 people from most States and New Zealand.

In brief, this is the overall situation regarding brain tumours in Australia:

- 1400 Australians are diagnosed annually with a malignant primary brain tumour; a similar number are diagnosed with so-called benign brain tumours; and an estimated 8,000 suffer metastases to the brain from a cancer elsewhere in the body.
- Brain tumours are responsible nationally for more cancer deaths than all leukaemias among children fourteen years and under.
- 1200 people a year die from a brain tumour.
- Although ranked only 15th in terms of incidence among all cancers, brain tumours are ranked 4th in the table of Person Years of Life Lost (PYLL) as a result of cancer deaths in Australia.

- Only 2 Australian males under 40 years of age were treated for prostate cancer in 2000 (latest available national statistics) and no female under 15 years of age was treated for breast cancer - two of the most common cancers - but babies of only a few months are treated for malignant brain tumours every year. Brain tumours do not discriminate by age but attack males and females in all age categories. They practise "equal opportunity".
- Screening for primary brain tumours is impractical and would be uneconomical. Unlike some other cancers there is no known scheme of early detection which can assist in management of the disease.
- New research indicates that brain tumour patients who have undergone recent neurosurgery may exhibit significant psychosocial effects of maladaptive behaviour not experienced by those with other cancers.
- No link has yet been found between the occurrence of a brain tumour and an unhealthy lifestyle, diet, smoking etc. For example, in regard to the 'popular' area of research (mobile phones) many newly-diagnosed patients in their 'fifties and 'sixties have never owned or used a mobile phone.
- Finally, nothing much has happened in the past twenty years: the five-year survival rate of 24% has remained stuck at that level since the 1980s, whereas the survival rates for most other cancers have improved..

The treatment of brain tumours has become lost between traditional treatments for cancer and established service provisions for those with an acquired brain injury (ABI) resulting from an industrial or automobile accident. On the one hand, brain tumours represent a minority share of the workload of a general neurosurgeon, and a minority share of the cases dealt with by most oncologists. Consequently, we lack in Australia areas of specialisation in the treatment and care of people with a brain tumour.

At our most recent BTA Workshop Associate Professor David Andrewes, who is a neuro-psychologist from the Department of Psychology at the University of Melbourne, presented early findings from research he has been undertaking on brain tumour patients who have had neurosurgery:

"In a recent paper published in the Journal of Clinical Neuroscience our research shows that all the tumour patients are rated by their partners as having significant emotional and social problems compared to a control group of patients. The control group includes patients with cancer to non-brain areas and other neurological patients, some of whom are suffering chronic pain.

"The results of the study show there are high levels of anger and depression. But there is also, perhaps predictably, high levels of fatigue. Perhaps less predicted from a layman's view are the high levels of indifference and maladaptive and inappropriate behaviours.

"Patients themselves recognise most of these problems according to their self-ratings on similar scales, however, they are less likely to recognise the inappropriate or maladaptive behaviours. e.g. childish, embarrassing and unreasonable behaviour, which are reported by the partner. The partners indicate that patients often have especially poor insight into these last problems.

"As can be seen it is the malignant tumour patients who show the most problems and these levels are also far in excess of levels reported for stroke and multiple sclerosis patients according to two studies which are in preparation for publication. (My emphasis).

"Part of the extra problems of these patients with malignant tumours probably relates to their poor prognosis. However, this is unlikely to be the whole story since in my control group I have equal proportions of cancer patients who were seen as having terminal illness. Therefore there is likelihood, supported by my other studies, that some of the difficulties are related to the effects of brain damage. This is not a good argument for not having Surgery, however, because the tumours had been left they could have eventually resulted in similar damage to the brain and we have no way of telling what these patients were like prior to surgery.

"Finally there is a general effect, which I find in most of my studies that male patients are reported to have more problems when compared to females. However, this is not to underrate the very significant problems suffered by all these patients."

As I recall, Professor Andrewes study was confined to adults with partners but his findings are probably equally as valid for young adults, teenagers, and children. His findings need to be made known to all health professionals who have routine contact with brain tumour patients in a hospital, nursing home, community nursing, or palliative care situation because I do not believe they are currently understood.

Unless the patients are in some form of institutional care, be it a hospital or nursing home, they are unlikely to have access to rehabilitation services. I note, for example, that in the ACT referral to a neuropsychologist as part of the public health system appears to be dependant on registration under the mental health provisions. Brain tumour patients often suffer from major cognitive deficiencies and are in need of neuropsychological assessment and assistance but their needs are not related to mental illness. Lack of access to experienced neuro-psychologists has been identified as a problem by patients and carers at the workshops and meetings we have held.

From anecdotal information received by me in the course of public meetings we have held to date and extensive communication with carers and family members, the problem concerning residential accommodation relates to: (1) the unpredictability of the course of the tumour, and (2) an absence of respite care opportunities and suitable accommodation facilities either for brain tumour patients who suffer from major neurological deficits or are in the end stages of the disease.

Unpredictability: The journey of those who have been diagnosed with a *malignant* primary brain tumour has been characterised as a "roller coaster ride". At one stage the patient might be capable of leading a reasonably "normal" life, able to care for themselves, and interact with others. Suddenly they might suffer a convulsion and new deficits of paralysis, speech, incontinence, etc might occur. Often, this will result in hospitalisation. If they are discharged, most families will attempt to care for the patient at home, either with the assistance of community nursing or home based palliative care support. Others are incapable of returning home and sometimes occupy hospital beds for lengthy periods, in lieu of the availability of alternative

accommodation, either in a hospice or a nursing home. Whatever one thinks about the appropriateness of this in terms of the efficient use of resources, the very presence in a hospital can often provide access to advice and diagnostic services not readily available elsewhere.

For example, let us say that a brain tumour patient experiences a seizure which is associated with, or manifests itself in, a deficit relating to taste. Experienced staff in a neurological or inpatients oncology ward will have encountered this previously and may ask a hospital-based dietician to advise the patient about variations in the types of food eaten which will assist in coping with this problem.

Similarly, a hospital-based rehabilitation specialist may be able to advise the patient about how to cope with some form of paralysis which has developed.

Absence of respite care: Inadequate financial assistance to palliative care services has resulted in extreme pressure on palliative care services throughout Australia and a consequent abandonment in many cases of a *respite care* service for people with a terminal illness.

Respite care for the patient is in strong demand in any event but respite care opportunities *within a hospice setting* appear to be fast disappearing.

At the same time, these pressures have acted against some brain tumour patients who are not in the end stages of the disease but have progressed beyond a point where their family is able to look after them at home. I recall one oncologist in a major city telling me that she was required to sign a form for admission of a brain tumour patient to a hospice which contained a declaration that in her opinion the patient would die within three weeks.

One cannot always make such predictions with great certainty and certainly not with a brain tumour patient. Furthermore, a patient who is deteriorating from the effects of a so-called "benign" tumour which is incapable of further surgery but which is slowly destroying adjacent brain cells by pressure, can linger for several months and hospices, by their nature, are not geared to accommodate such people; neither are many nursing homes.

I trust that the above information will be useful to your Inquiry. I believe that the issue may be inter-related with the absence of suitable end of life services and residential care facilities for young people with a terminal illness and perhaps there will be an Inquiry into that subject one day. As stated above, malignant brain tumours, unlike the more common cancers, attack people from all age groups.

Yours sincerely

Denis Strangman
Chair