



## **MEDIA RELEASE**

**Friday, 21 January 2011**

### **BRAIN TUMOUR CARE COORDINATORS – SUBMISSION TO THE FEDERAL TREASURER AND RESULTS OF SURVEY**

Brain Tumour Alliance Australia (BTAA), which represents brain tumour patients and carers, has responded to an invitation by the Treasurer for submissions from the public to the Federal Budget, by seeking funds to support the creation of positions for brain tumour care coordinators.

BTAA Chair Matt Pitt said that the need was strongly supported by a recent survey of patients and their carers and health professionals in all States and Territories.

”A care coordinator is a staff member in a cancer treatment centre who acts as a focal point for patients and their families and helps guide them through the health bureaucracy and treatment maze.

”We are mindful that the Queensland floods will have an impact on the 2011 Federal Budget but unfortunately cancer stops for no one and brain tumours can be one of the most lethal of all cancers.

”It is the cancer which killed Professor Chris OBrien, Senator Ted Kennedy, journalist Matt Price, and only last Sunday it took the life of Cold Chisel drummer Steve Prestwich.

”There are already generalist cancer care coordinators and others for specific cancers, such as breast, but the number for brain tumour coordinators is relatively small when one considers the complicated nature of the patients' treatments and the deficits they can suffer.

”Brain tumours cause both physical and neurocognitive problems along with personality change in some instances. They cause complex health issues and require intervention from numerous specialities including neurosurgery, radiotherapy, medical oncology, neurology, and palliative care, to name a few.

”Patients and families need to steer an extremely complex and intense pathway through medical facilities and even the toughest of patients soon become overwhelmed and confused. Mr Pitt said.

”131 brain tumour patients, their carers, and health professionals who work in the area, took part in our survey and overwhelmingly supported the need for more cancer-specific care coordinators. (A 26 page report of the survey, which contains more than 60 representative comments from the 131 respondents has been uploaded to the web at: <http://www.btaa.org.au/CareCoordinatorSurvey.pdf> ).

”At the present time there are two coordinators working in the paediatric area and nine in the adult area but some of those are only paid for a couple of days a week. Furthermore, some of the current coordinators are reliant on one-off philanthropic or benevolent industry sources of funding. About 1400 Australians each year are diagnosed with a primary malignant brain tumour, one of the most lethal cancer diagnoses, however, the majority of patients and families are missing out on this service.

Commenting in the survey on their experiences patients and family members said such things as: “The overwhelming time after diagnosis is a maze which we stumbled through without help targeted specifically at brain tumour patients. We made potentially deadly decisions through lack of knowledge of the disease, its impact and treatment/specialist options.

A family member commented: “It has been extremely frustrating trying to get information and advice urgently and we have often had to resort to using the internet or our family GP to get quick answers.

A husband wrote: “Since 10/05 when my wife was diagnosed we still are not aware of any such support. It is desperately needed. Patients diagnosed with brain tumours and their carers feel lost and neglected by the "system" which they have to try to navigate themselves.

Sydney oncologist Dr Helen Wheeler, who probably sees more brain tumour patients than any other oncologist in Australia, is full of praise for the care coordinator in her clinic: “She allows me to double the number of patients seen as I know she will be there to back everything up”.

Brisbane neurosurgeon Dr David Walker helped create a care coordinator position in the BrizBrain practice several years ago and the position is now an integral part of what is offered to patients and their carers.

But many other treatment centres are not so fortunate and funding sources turn a blind eye.

Jon Jordans from Adelaide, whose sister died from a brain tumour, made three unsuccessful applications on behalf of the Adult Brain Cancer organisation for funding for a coordinator’s position in Adelaide, despite having the strong support of specialists and staff working in the area.

Mr Pitt is hopeful that the BTAA approach to the Treasurer will be successful. “It is not going to

require vast amounts of money but a small amount of key funding could make an enormous difference to many patients and their families.

“It is consistent with the Government’s commitment to use health care resources efficiently, giving brain tumour patients the right treatment at the right time and avoiding delays that make treatment ineffective and this can all be achieved with a reduced workload for medical specialists,” Mr Pitt said.

### **Canberra**

The following people are available to comment on the subject:

Mr Matthew Pitt (brain tumour survivor, Canberra) 0420 804 828

Ms Sarah Mamalai (brain tumour survivor, Canberra) 0420 949 990

Ms Renee Hindson (brain tumour survivor currently receiving treatment, Canberra) 0439 994 600

Mr Jon Jordans (former caregiver, Adelaide) 0438 832 108

Ms Marina Kastelan (care coordinator in Dr Wheeler’s clinic, Sydney) 02 8425 3610

Dr David Walker (neurosurgeon, Brisbane) 07 3833 2500

Dr Eng-Siew Koh (radiation oncologist Sydney) 02 9616 4457

Brain Tumour Alliance Australia Inc. Freecall number (free from landlines only): 1800 857 221.

Denis Strangman (Secretary), PO Box 76, Dickson ACT 2602