



Brain Tumour Alliance Australia (BTAA) Inc
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BRAIN TUMOUR ADVOCACY GROUPING APPEALS FOR 'CRITICAL' NURSING SUPPORT

MEDIA RELEASE

FRIDAY 25 OCTOBER 2013

A national alliance of advocates for the thousands of Australians suffering brain tumours will on Sunday, 27 October, launch a major appeal for the establishment of a national care coordinators network. The launch, being held in Sydney at the first national meeting of Australia's brain tumour advocacy groups, will confirm the network as its major priority as a means of marking the start of International Brain Tumour Awareness Week (27 October – 2 November).

The Chair of Brain Tumour Alliance Australia (BTAA), Matthew Pitt, described as “absolutely vital” a national network of care coordinators specialising in helping not only those diagnosed with the most dangerous and often most deadly disease of all but also their families and carers.

“A Specialist Brain Tumour Care Coordinator Program is urgently needed so as to provide expertise, advice, comfort and relief to those in the most dire health predicament imaginable,” Mr Pitt said.

“Brain tumours cause complex health problems and require intervention from numerous specialities, including neurosurgery, radiotherapy, medical oncology, neurology and palliative care - to name a few.

“A national, coordinated program is required, that provides care coordinators expert in brain tumour treatment and care in as many hospitals as possible, so as to help patients and their families through the many health, treatment and bureaucratic problems they will encounter.”

Mr Pitt emphasised that brain cancer is the highest cause of death through disease for children aged up to 14 years and the highest cause of death from cancer in all people aged up to 39 years.

“Yet appeals for assistance for brain tumour patients and their carers tend all too frequently to fall on deaf ears,” he said. “Efforts to ensure help for people in the most desperate health situation imaginable have thus far been largely ignored.”

Mr Pitt said that for those suffering other forms of cancer, notably breast and prostate cancer, support structures have been in place for years and survival rates for these diseases are increasing exponentially.

“But those with the worst prognosis of all appear to be receiving the least attention,” he said. “Little wonder the mortality rate among those with brain tumours is so high and that long-term survivors of malignant brain tumours are all too rare.”

The BTAA president added that what so often compounds the problem for those receiving a brain tumour diagnosis is the lack of guidance available.

“All too often patients and their carers are left to fend for themselves”, he said. “They frequently describe their treatment experience as ‘like being in a bewildering maze’. They have to negotiate an extremely complex and intense pathway, with little advice offered or available regarding the variety and frequency of treatments involved, the high costs associated with vital medication, and the availability and location of specialist expertise. Given the deficits the disease can produce it’s little wonder that even the toughest of patients soon become confused and overwhelmed. We are therefore appealing for the establishment of a national network of brain tumour care coordinators.”

Mr Pitt said there are currently only about twelve specialist brain tumour care coordinators in Australia. He said he would continue to advocate for these neuro-oncology care coordinators so that one day every newly-diagnosed patient/family has access to a health system ‘navigator’.

Matthew Pitt speaks from experience. In 2001, at the age of 19, he was diagnosed with a so-called ‘benign’ brain tumour. After completing his treatment he embarked on a mission to help others and in 2008 co-founded BTAA, currently the only national organisation providing information resources to newly diagnosed patients and their families.

“So I am one of the lucky ones”, he declared. “But for far too many Australians, there is no help, no luck – and no future.”

Mr Pitt has appealed to all those affected by the diagnosis of a brain tumour to speak to their elected members of Parliament about the special needs of patients and their families.

He said Commonwealth funding would assist in the examination of models of care so that brain tumour patients, carers and health professionals received support and people were not ‘lost’ in the system. He believes the proposed program should be allowed to operate in public hospitals, through Medicare Locals, or in private settings.

Mr Pitt further suggested that the proposed program be coordinated by the Department of Health, and a consortium of consumer health organisations led by BTAA. This funding model would draw from the Federal Government’s recent commitments to the McGrath Foundation’s advocacy of breast care nurses and the Prostate Cancer Specialist Nursing Program.

Ends

Further information/comment:

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Contact Susan Pitt, Secretary, BTAA, to be linked to other contacts across Australia,

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Facts and Statistics about Brain Tumours <http://www.btaa.org.au/FactSheet080313.pdf>

BTAA IBTA Week newsletter <http://www.btaa.org.au/LowResOct2013.pdf>

BACKGROUND MEDIA INFORMATION

A brain tumour is the only cancer to affect both the mind and the body

Specialist nurses/care coordinators for brain tumour sufferers was the key priority identified in a survey of patients and health professionals in 2012. Among others were:

- The need for more research funds for the study of gliomas, the most deadly of all brain tumours, from which few survive;
- The need for the rapid evaluation – and approval and subsidisation where appropriate – of new therapies available to brain tumour patients overseas but not yet to those in Australia.

The cost, financial and emotional, of maintaining some quality of life for brain tumour patients is massive. A brain tumour diagnosis incurs the largest lifetime financial costs faced by households of any cancer type, at \$149,000 per person, and produces the highest lifetime economic cost of any cancer type, at \$1.89 million per person.

Brain tumour research funding is low in relation to the burden of the disease – as is research funding for lung cancer and mesothelioma, bladder cancer, pancreatic cancer and lymphoma.

The twelve existing positions for brain tumour care coordinators in Australia vary from two days per week to 50 hours per week. By contrast, the Cancer Institute NSW funds 58 generalist cancer care coordinators for NSW alone.

BTAA has contacts for people living with brain tumours willing to share their stories to raise awareness of the disease upon request.

BTAA has contact for health professionals with a particular or exclusive interest in brain tumours. They can provide informed comment on the value of adequately funded clinical trials to validate promising therapies already in use by some clinicians, such as 5-ALA guided resection and PET tracer imaging diagnostics, as well as the promising genetic testing to enable better targeting and better clinical research.

Authorised by Matt Pitt, Chair, BTAA, www.btaa.org.au Freecall 1800 857 221
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