



Brain Tumour Alliance Australia Inc
Submission to the 2011–12 Federal Budget
January 2011

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Definition:

Central nervous system (CNS) neoplasms are commonly referred to as brain tumours. The central nervous system comprises the brain, the meninges, the spinal column and other areas. This report uses the term brain tumour to include all CNS neoplasms unless otherwise specified.

About Brain Tumour Alliance Australia (BTAA) Inc

- BTAA is the only national patient and caregiver organisation in Australia. BTAA is a not for profit organisation established in 2008 by a group of brain tumour patients and current and former care givers.
- BTAA is concerned about all brain tumours (neoplasms) of the central nervous system (CNS), which includes the meninges, brain and spine.
- Whilst welcoming the advice and input of health care professionals, BTAA seeks to represent the brain tumour community from the viewpoint of the patient, family and caregiver. BTAA is incorporated in the Australian Capital Territory.
- BTAA coordinates and liaise between organisations, groups and service providers with an interest in central nervous system (including brain) malignant (cancer) and benign tumour care and support.

BTAA seeks to:

- guide improvements to brain tumour research, treatment and care;
- ensure health consumers treatments are based on the best available evidence;
- make recommendations to government about brain tumour policy and priorities; and
- guide government and health professionals in brain tumour policy and programs.

BTAA is a new member of the Consumers Health Forum of Australia. More information on BTAA is available at www.btaa.org.au

During 2010 BTAA partnered with *beyond blue* to [produce a fact sheet for people living with brain tumours on depression and anxiety](#), launched by Ms Leonie Young, CEO of *beyond blue* and Tasmanian Senator Catryna Bilyk at Parliament [House on 28 October 2010](#) on behalf of the [Parliamentary Brain Tumour Awareness Group](#) (BTAG). Representing the Minister for Health and Ageing, the **Hon. Nicola Roxon MP**, Senator Bilyk said “Nationally brain tumours affect about 1,400 people diagnosed with malignant brain tumours each year with another 1,400 diagnosed with benign tumours. However, brain tumours can have a significant impact on both the physical and mental health of sufferers.” A copy of Senator Bilyk's media release can be accessed [here](#). More information on BTAA is available at www.btaa.org.auMore

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Executive summary

Definition: Central nervous system (CNS) neoplasms are commonly referred to as brain tumours. The central nervous system comprises the brain, the meninges, the spinal column and other areas. This report uses the term brain tumour to include all CNS neoplasms unless otherwise specified.

The Problem

Brain tumours can affect a person at any age, and unlike many other cancers and diseases, there is no known cause or prevention. From a health public point of view brain tumours are particularly challenging causing both physical and neurocognitive damage along with personality changes in some instances. Brain tumours are the only cancer to affect both body and mind; they strike at the very essence of a person. Brain tumour patients face particular difficulties and have relatively very little support in the community and very limited support from cancer organisations including health consumer organisations. Unlike some other cancer survivors in Australia, brain tumour survivors have been unable to organised philanthropic support for care.

In economic framework terms brain tumours present a special case for government intervention to address ‘market failure: in particular there is ‘information failure’ in the sense that brain tumours can impair decision making and judgement and compound the challenge of treatment.

Official statistics show brain tumours (malignant and benign) are responsible for more than 1,400 deaths a year in Australia, and ranks 5th in terms of life years lost from disease¹. (See **Chart 1** and **Table 1** below).

Given the high mortality rates of malignant brain tumours, brain tumours overall have a relative low survival rate compared with other cancers. Malignant brain tumours are the second highest cause of death for children aged one to 14 years, second only to accidental drowning (**Table 3** below).

¹ After Malignant neoplasms of the bronchus and lung (C34) - 60,561, Chronic Ischaemic Heart Disease (I25) - 53,763 , Acute myocardial infarction (I21) - 35,396, Malignant neoplasm of breast (C50) - 34,475

Brain tumours cause complex health issues and may require intervention from numerous specialities including neurosurgery, radiotherapy, medical oncology, neurology, and (too often) palliative care. Combined chemo-radiotherapy is now standard care for glioblastoma brain tumours and brings with it particular challenges and side-effects.

According to research conducted by Brain Tumour Alliance Australia (BTAA) Inc. in January 2011, at the present time in all of Australia there are only eleven brain tumour care coordinators, or system navigators. They include two working in the paediatric area and nine in the adult area, some on a part time basis. Furthermore, some of these coordinator positions are reliant on philanthropic or industry sources of funding from year to year.

With more than 1400 Australians of all ages each year diagnosed with a primary malignant CNS tumour — one of the most lethal cancer diagnoses - the vast majority of patients and families are currently missing out on much needed care coordinator. There is strong evidence for a greater focus on CNS tumours, led by the Australian Governments to improve diagnosis and treatment that will reduce mortality and morbidity and increase survival times.

Policy response recommendations:

1. Central nervous system tumours (including brain tumours and other central nervous system tumours {malignant and benign) be recognised **as an Australian Government national health priority**, in collaboration with the State and Territory Governments, as an initiative to focus public attention and health policy on the significant burden of this disease in Australia in terms of incidence, and person life years lost. There is potential for significant gain in terms of the quality of life of both patients and families, and their contribution to Australia.
2. That the Australian Government provide funding of **\$12 million over four years (\$3 million per annum)** commencing in 2011-12, for the creation of an additional 10 – 15 brain tumour care coordinators.
 - a. This funding be provided to treatment centres where there is interest and administrative support, and made available if required to ensure continuity of funding of the approximately 11 existing central nervous system (including brain) care coordinators (some part time).

- b. This funding be administered by the Department of Health and Ageing and allocated on a new model, informed by the results of the BTAA Survey about brain tumour care coordinators undertaken by BTAA in January 2011 (**separate Attachment**). In metropolitan centres it is envisaged the positions would be full-time whilst in regional centres they may be varying Full Time Equivalent (FTE) levels or combined with other cancers.
 - c. It is envisaged such funding would allow for the recruitment and training of specialist central nervous system (brain) cancer care coordinators by hospitals and other health service providers and State/Territory Cancer Councils on a needs basis.
 - d. It is also envisaged people living in rural and remote areas could be given access via E-health initiatives.
 - e. Special consideration should be given to establishing a national dedicated 24 hour telephone service staffed by specialist nurses for existing patients, for advice on managing side effects of treatments (including medications).
 - f. BTAA sees our role in implementing a new program as providing consumer advocate assistance and liaison with health professionals.
3. BTAA seeks Australian Government support in the form of administrative funding and coordination for the collection, collation and dissemination of data on called benign brain tumours in the State and Territory Cancer registries to allow proper consideration of the burden of the disease and impact on the health system of these life threatening and often disabling tumours.
- g. BTAA has not estimated the costs of this but notes it is collected by some cancer registries but needs a nationally consistent reporting framework developed. The National Health Information Standards and Statistics Committee at AIHW could provided advice on costings to get a national data set established.

BTAA's [Survey about brain tumour care coordinators](#) provides further information on the existing role and function of these health professionals, as well as their potential. The Survey provides information on the qualifications and titles for the role. In terms of international practice see www.floridahospitalbrainspinecancer.com for video and an outline of the role of brain and spinal cancer care coordinators, including: coordinating/scheduling/expediting care among providers, ensuring patients have the necessary information to make fully informed decisions on treatment, assisting with second opinions, providing education about procedures, diagnosis and treatment in easy to understand terms, services as a link between the patient and the health professionals, and connecting patients and families with resources including income support, palliative care.

Introduction

This submission by BTAA focuses attention on the public policy implications and the evidence for a special case for support for brain tumour patients and their families and carers and community.

The key recommendation is to provide funding to support increased access to brain tumour care-coordinators to assist brain tumour patients, and their carers, to navigate, and deal with weaknesses and challenges in the Australian health care systems, both public and private.

BTAA calls for a doubling of brain cancer care coordinators to coordinate cancer care and treatment in a timely, seamless way to improve survival and quality of life for each patient

BTAA conducted research on the needs for brain tumour care coordinators through a survey conducted in December 2010 – January 2011. (Separate attachment including a definition of care coordinator and roles).

The 131 responses across all States and Territories provides strong evidence that health care professionals and consumers value the services of the small number of existing brain tumour care coordinators currently working in the Australian health system.

Patients and health professionals report that, where patients have had access to brain tumour care coordinators, it is evident that the outcomes are better.

Such care coordinators help patients and their carers navigate the complex health care system and enable more efficient access to choices available.

Workforce shortages for health care professionals are particularly acute for the various health professionals dealing with the particular challenges of brain tumour patients.

Specialist health care professionals, including neurosurgeons and oncologists, reported brain tumour care coordinators improve their efficiency and effectiveness by relieving their workload. They reported that they would be to see more patients were more care coordinators services available.

They also reported a high unmet demand for additional brain tumour coordinators, as well as uncertainty with respect to funding for existing coordinators – several of whom were funded on a non-ongoing basis by private organisations.

Health policy challenges

There are around 1,400 new cases a year of malignant brain tumours and hundreds more of so-called benign brain tumours that can be just as deadly if the tumour is in a vital area.

The burden of the disease is high in terms of morbidity and mortality and survival rates are not improving. [Australian Institute of Health and Welfare](#) (AIHW) five year survival statistics show no significant change in survival between 1982–1986 and 1998–2004 (21 per cent over 5 years). Brain tumours are the eight highest cancer causes of burden of disease, for both males and females². Brain tumour patients have the second longest average length of stay (12.5 days) in 2008-09.³

Brain tumours are not only a disease affecting older persons – 100 new cases a year of malignant tumours affect children, with a greater, but unknown number of benign tumours. Malignant brain tumours are the most common form of childhood malignancies.

According to a report from [Cancer Australia](#), relative to their burden on the Australian community, brain tumours are one of six cancers with proportionally low levels of research funding – along with lung cancer and mesothelioma, bladder cancer, pancreatic cancer, lymphoma and mesothelioma, and cancers of unknown primary site.⁴ Only 10 research projects associated with brain tumours were identified. Moreover, often research attributed as relevant for brain tumours is focused on other neurological conditions.

CNS tumours accounted for more than 5,000 hospitalisations in 2008-09. Health policy for CNS tumours (including brain tumour and other central nervous system):

- **is not amenable to initiatives to increase earlier detection through public education about screening programs, preventative health nor self-examination or recognition of symptoms;**
- but is amenable to more effective treatments, including ensuring equity across the states and territories and access to high quality treatment for those in regional and rural areas;
- is amenable to improved statistical collection of benign tumours to improve understanding of the resource implications;

² Cancer in Australia, An overview , AIHW, 2010, pg 61

³ Ibid, pg 68

⁴ Cancer in Australia, An overview of research projects and research programs in Australia 2003 – 2005, Cancer Australia pg 2

- is amenable to more effective investigation and staging of disease and more widespread availability of best practice treatments; and
- is amenable to increasing sub–specialisation of treatments, such as regional centres of excellence

Challenges for policy makers include access to data on so-called benign brain tumours to assess the needs of this low–profile group of health consumers. Excluding brain and other CNS tumours from official national statistics considerably underestimates the burden of the disease, particularly as international statistics infer the majority of tumours in those 18 and under are benign and a significant proportion of tumours in adults are benign.

Benign tumours can be fatal as an examination of the ABS causes of death data shows. Benign tumours can also be curable, but can also be disabling, necessitating life long high dependency nursing care in some cases and assistance with education and training for many.

BTAA understands some State/Territory cancer registries already collect data on benign or uncertain tumours of the brain and CNS, however it is not nationally consistent. Details of benign tumours are not provided to the AIHW and do not form part of the Australian Cancer Database.

Thus the incidence of benign CNS tumours are excluded from AIHW’s statistical collections and from survival calculations, whilst included in ABS Causes of Death statistics.

The remainder of this report provides evidence on the case for brain tumour care coordinators and supporting statistical information on cancers and brain tumours sourced from the ABS and AIHW.

Key facts about brain tumours

- Brain tumours need specialist care during diagnosis, treatment and rehabilitation.
- Better treatment leads to longer life expectancy and better neurological outcomes.
- There are more than 160 different types of brain tumours alone, of which some 40 are classified as malignant. It is possible that each type of tumour has different causal factors and its degree of malignancy (the grade of tumour), and its location affect its behaviour and treatment.

- There are three main categories: primary, “benign”, brain metastases (arising from a cancer elsewhere in the body).
- A primary malignant brain tumour is life threatening, invasive, and usually rapid growing. In contrast to tumours in other parts of the body, CNS tumours are confined by hard casing in the form of skull and vertebrae, leaving nowhere to grow into but structures such as the brain stem which controls respiration and cardiac rates, swallowing, consciousness, and other functions that determine life and death.
- Brain tumours account for the most cancer related deaths in children aged 0 – 14 years, and are the second highest cause of death in young children, after accidental drowning.
- More men are affected by primary CNS tumours than women but more women develop meningioma brain tumours (a benign form).
- Benign brain tumours are not published in Australian cancer registry statistics and they can be lethal or lead to life long disabilities.
- Causes of brain tumours are generally unknown; cannot be prevented by any known lifestyle changes or anything else; no early detection or general community screening is possible.
- The location of the tumour, grade, and the type of treatments undertaken and a range of other factors influence the impact on the patient, their abilities and prognosis.

Table 1 below provides a summary of the underlying cause of death for person in Australia, from central nervous system (CNS) tumours (neoplasms) for 2008 for both males and females.

The table also includes the years of potential life lost – which are higher compared to most other cancers because of the relative youth of many of those affected.

Table 2 below provides a summary for each State and Territory related to the selected Cause of death and ICD-10 code for CNS neoplasms categories included in Table 1 above. (Table 6 in the appendices provides a detailed breakdown for each category for the States and Territories, as well as Australia.)

Table 1. Underlying cause of death, malignant and benign CNS neoplasms, Australia, 2008

Cause of death and ICD-10 code for CNS neoplasms	Number			Years of potential life lost		
	Males	Females	Persons	Males	Females	Persons
Malignant neoplasm of meninges (C70)	2	10	13	80	104	186
Malignant neoplasm of brain (C71)	710	484	1,194	11,805	7,423	19,164
Malignant neoplasm of spinal cord, cranial nerves and other parts of	3	5	9	117	70	187
Benign neoplasm of meninges (D32)	30	47	77	57	289	349
Benign neoplasm of brain and other parts of central nervous system (D33)	5	2	8	134	21	158
Neoplasm of uncertain or unknown behaviour of meninges (D42)	4	0	2	6	0	6
Neoplasm of uncertain or unknown behaviour of brain and central nervous	74	82	156	885	581	1,465
Total Australia	828	630	1,459	13,084	8,487	21,513

Source: Australian Bureau of Statistics (ABS) Causes of Death, Australia, 2008 (ABS Cat. no. 3303.0).

Table 2. Underlying cause of death, malignant and benign CNS neoplasms, States and Territories. Australia, 2008

Cause of death and ICD-10 code for CNS neoplasms	Number			Years of potential life lost (f)		
	Males	Females	Persons	Males	Females	Persons
NSW	252	217	470	3,804	2,706	6,498
Victoria	224	156	373	3,285	2,230	5,488
Queensland	172	117	286	2,963	1,547	4,500
South Australia	78	46	125	1,129	702	1,826
Western Australia	75	60	132	1,290	616	1,901
Tasmania	28	22	51	407	235	636
Northern Territory	3	2	2	66	89	150
ACT	8	15	24	81	342	421
Total Australia	828	630	1,459	13,084	8,487	21,513

The two charts below present causes of death for all central nervous system neoplasms (tumours) both malignant (cancerous) and benign, including brain, spine and meninges but excluding eye. Adjusting for population sizes of 18.8 and 21.5 million, the mortality rate from CNS tumours in 1998 was approximately 6.17/100000 persons, increasing to 6.79/100000 persons by 2008.

**Chart 1. Underlying cause of death, malignant and benign CNS neoplasms
Total number of persons, 1998 to 2008**

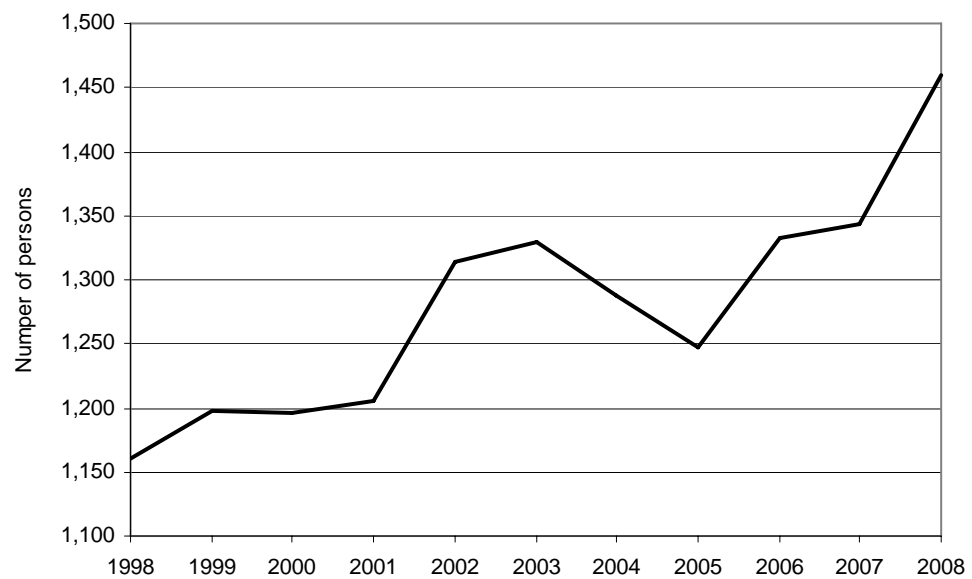
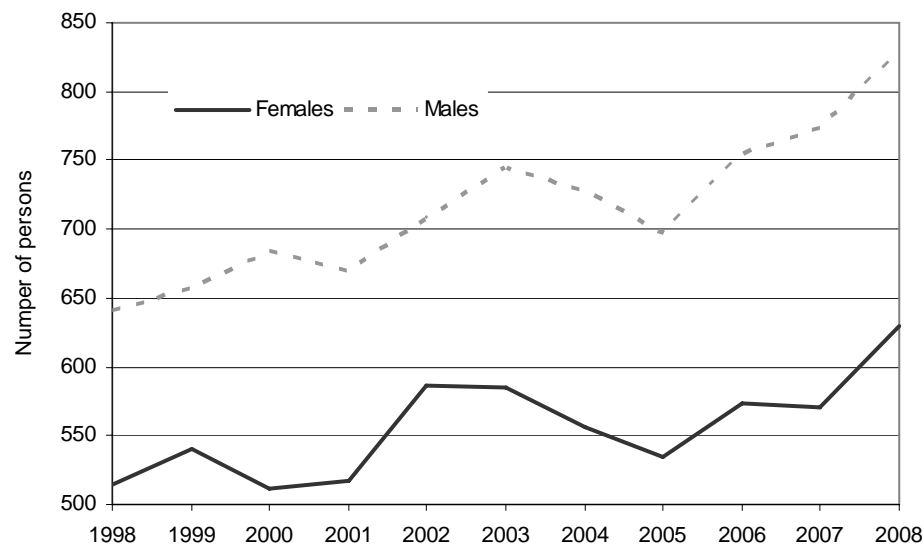


Chart 2. Underlying cause of death, malignant and benign neoplasms number of persons by sex, 1998 to 2008



Source: Australian Bureau of Statistics (ABS) Causes of Death, Australia, 2008 (ABS Cat. no. 3303.0).

Data cells with small values have been randomly assigned to protect the confidentiality of individuals. As a result, some totals will not equal the sum of their components. Cells with a zero value have not been affected by confidentialisation.

Survival trendsⁱ

The following survival statistics provided by the Australian Institute of Health and Welfare National Cancer Statistics Clearing House, drawn from the State and Territory Cancer Registers and ABS Causes of Death data.

Note the data below refers only to malignant (cancerous) brain tumours and thus excludes other malignant central nervous system tumours and all benign CNS tumours.

The statistics demonstrate the lack of improvement in survival rates for both adults and children with brain tumours.

- For both males and females, brain cancer showed no significant change in five-year relative survival between 1982–1986 and 1998–2004. In contrast, 5-year relative survival from all cancers for males/females increased from 41/53 per cent in 1982–1986 to 58/64 per cent in 1998–2004, respectively.
- Cancers with the lowest five-year relative survival in 1998–2004 were pancreatic cancer (4.6 per cent), cancer of unknown primary site (9.1 per cent), lung cancer (12 per cent), **brain cancer (19 per cent)** and stomach cancer (25 per cent).
- Cancers with the highest 5-year relative survival in 1998–2004 were testicular cancer (97 per cent), thyroid cancer (93 per cent), and melanoma of the skin (92 per cent), breast cancer (88 per cent) and prostate cancer (85 per cent).

Changes in 5-year relative survival between 1982-86 and 1998-2004 for cancers presented in Australia's Health 2008 (AIHW, 2008; pp 192-193) is shown in a retabulated form below (tables 3 and 4). Brain tumours have the dubious distinction of being the only cancers that experienced *decreases* in 5-year relative survival between 1982 and 2004.

Table 3. Change in 5-year relative survival between 1982-1986 and 1998-2004 for cancers in females presented in Australia's Health 2008 (AIHW, 2008; pg 179)

	1982-1986	1998-2004	total change (%)	(% relative change)
stomach	18.2	25.3	7.1	39.0
kidney	48.8	66	17.2	35.2
lung	10.5	14	3.5	33.3
non-hodgkin lymph	47.6	62.6	15	31.5
leukeamia	37.2	47.3	10.1	27.2
colorectal	49.7	62.4	12.7	25.6
breast	71.8	87.8	16	22.3
ovary	32.7	39.8	7.1	21.7
all cancers	53.2	64.1	10.9	20.5
hodgkin lymph	71.3	85.8	14.5	20.3
thyroid	85.3	95.3	10	11.7
body of uterus	75.6	82.1	6.5	8.6
cervix	68.3	71.8	3.5	5.1
melanoma	90.5	94.1	3.6	4.0
brain	19.9	19.4	-0.5	-2.5

Table 4. 5-year relative survival between 1982-1986 and 1998-2004 for cancers in males presented in *Australia's Health 2008* (AIHW, 2008; pg 178)

	1982-1986	1998-2004	total change (%)	(% relative change)
stomach	16.2	24.4	8.2	50.6
prostate	57.4	85.3	27.9	48.6
kidney	45.2	65.6	20.4	45.1
all cancers	41.3	58.4	17.1	41.4
lung	7.9	10.7	2.8	35.4
non-hodgkin lymphoma	46.3	61.6	15.3	33.0
colorectal	47.7	61.3	13.6	28.5
leukaemia	37.9	48.2	10.3	27.2
hodgkin lymphoma	72	84.8	12.8	17.8
thyroid	79.1	87.7	8.6	10.9
melanoma	82.2	89.7	7.5	9.1
testis	90.8	96.8	6	6.6
brain	20.8	18.5	-2.3	-11.1

Children and teenagers

- Australian Bureau of Statistics underlying cause of death data show malignant brain tumours are the second highest cause of death for children aged 1 – 14 years, after accidental drowning (Table 3 below).
- Australian Institute of Health and Welfare data reports that cancer survival for children aged 0–14 years was relatively high, with an all-cancer 5-year relative survival of 79 per cent for children diagnosed in 1998–2004. But for children aged 0–14 years, 5-year relative survival from **cancers of the brain and central nervous system** decreased between 1982–1986 (57.5 per cent) and 1998–2004 (56.2 per cent).
- Of the three most common childhood cancers, only leukaemia showed a significant increase in 5-year survival from 64 per cent in 1982–1986 to 83 per cent in 1998–2004.ancer trends.
- Paediatric brain and spine tumours are particularly difficult for families to face – partly because of the devastating nature of the disease, and partly because of the lack of coordination for the specific services required by young people facing this diagnosis.

Table 5. Underlying cause of death, Age at death, 1 to 14 years, numbers and rates, Australia, 2007 and 2008

Cause of death and ICD-10 code	Number			Age-specific Death Rate (a)		
	Males	Females	Persons	Males	Females	Persons
2007						
1–14 years						
All Causes	294	212	506	15.1	11.4	13.3
Accidental drowning and submersion (W65-W74)	22	16	38	1.1	0.9	1.0
Malignant neoplasms of eye, brain and other parts of central nervous system (C69-C72)	20	17	37	1.0	0.9	1.0
Car occupant injured in transport accident (V40-V49)	13	13	26	0.7	0.7	0.7
Metabolic disorders (E70-E90)	12	10	22	0.6	0.5	0.6
Other forms of heart disease (I30-I52)	12	10	22	0.6	0.5	0.6
Pedestrian injured in transport accident (V01-V09)	7	12	19	0.4	0.6	0.5
Cerebral palsy and other paralytic syndromes (G80-G83)	11	7	18	0.6	0.4	0.5
Congenital malformations of the circulatory system (Q20-Q28)	9	9	18	0.5	0.5	0.5
Malignant neoplasms of lymphoid, haematopoietic and related tissue (C81-C96)	6	10	16	0.3	0.5	0.4
Episodic and paroxysmal disorders (G40-G47)	9	7	16	0.5	0.4	0.4
2008						
1–14 years						
All Causes	293	208	501	14.9	11.1	13.1
Accidental drowning and submersion (W65-W74)	17	12	29	0.9	0.6	0.8
Malignant neoplasms of eye, brain and other parts of central nervous system (C69-C72)	14	14	28	0.7	0.7	0.7
Metabolic disorders (E70-E90)	19	6	25	1	0.3	0.7
Car occupant injured in transport accident (V40-V49)	15	9	24	0.8	0.5	0.6
Malignant neoplasms of lymphoid, haematopoietic and related tissue (C81-C96)	12	8	20	0.6	0.4	0.5
Congenital malformations of the circulatory system (Q20-Q28)	9	8	17	0.5	0.4	0.4
Episodic and paroxysmal disorders (G40-G47)	8	8	16	0.4	0.4	0.4
Chronic lower respiratory diseases (J40-J47)	11	1	14	0.6	0.2	0.4
Cerebral palsy and other paralytic syndromes (G80-G83)	5	7	12	0.3	0.4	0.3
Other forms of heart disease (I30-I52)	2	8	12	0.2	0.4	0.3
Congenital malformations of the nervous system (Q00-Q07)	5	7	12	0.3	0.4	0.3
Assault (X85-Y09)	7	5	12	0.4	0.3	0.3

Research findings

BTAA undertook a survey about brain tumour care coordinators in January 2011. The preliminary results and comments were released on 21 January accompanied by a media release (attached below). The initial report is available on the BTAA web site - <http://www.btaa.org.au/MediaReleaseCareCoordinators.pdf>

An excerpt is included below

EXECUTIVE SUMMARY

- There were 131 respondents from all States and Territories.
- This was the first national survey of its type carried out in Australia.
- Information was received from patients, carers, family members, and all main elements of the health profession who deal with brain tumour patients
- There are eleven existing positions for brain tumour care coordinators throughout Australia but these 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.
- Most patients and caregivers (42/62) had not been able to access a brain tumour care coordinator.
- There was overwhelming support by patients and carers (48/1) and members of the health profession for these positions.
- A number of treatment centres had sought to establish these positions but funding had been a problem.
- The care coordination role is often undertaken by nurses who have not been formally allocated this role and there is limited or no capacity to expand their contribution, with a number complaining that they cannot undertake these functions adequately.
- Patients and carers often described their treatment experience as being like in a bewildering maze, compounded by the deficits which the disease can produce.
- A call is made for funding from the Federal Government for financial support of existing brain tumour care coordinator positions and for the creation of extra positions, possibly of varying FTE (Full Time Equivalent) levels, in treatment centres where there is interest and support.

BTAA is the only national patient and caregiver organisation in Australia. In January 2011 it distributed an electronic survey via the Zoomerang survey program (www.zoomerang.com) to the email addresses of 455 people from Australia on its database. These addresses had been accumulated since the organisation's foundation in 2008 and included patients, their caregivers, and health professionals involved in their care, plus many others having some connection or interest in brain tumour matters.

A letter drawing attention to the web URL at which anyone could complete the survey was also posted to another 50 people on the BTAA database whose email addresses were unknown.

The survey sought answers to questions relating to the subject of brain tumour care coordinators and is believed to be the first national comprehensive survey of its kind on the subject. The questions are reproduced at Appendix A.

The 455 people to whom the survey was sent electronically were also sent a reminder by email if they had not yet completed it.

At least two state-based brain tumour patient organisations, one national cancer research organisation, and one State-based cancer control organisation, on-forwarded the access details for the survey to other contacts. Many individual recipients did likewise, sending it particularly to people who they believed may have had direct knowledge of the subject matter. The survey access details were also sent to members of an Australia-wide patient and caregiver email discussion list.

Response rate

83 valid responses were received from the original 455 email recipients and a further 48 as a result of the additional invitation methods described above, making a total of 131. One respondent was excluded because they lived in New Zealand; four recipients of the email invitation to BTAA contacts opted out of the survey; eight may not have received the original invitation email because of "hard bounces" and nine because of "soft bounces" (i.e. the email may not have been delivered because of a mail system malfunction or a "spam trap").

The response rate was 18% from the BTAA email invitation (83/455). The combined total of 131 respondents came from all States and Territories and covered the key components of health services that are accessed by brain tumour patients in Australia. The following table summarises the category and location of the 131 respondents:

Table 6. Respondents to the email survey regarding brain tumour care coordinators

Category/State	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Unk	Total
Family member	5	0	1	1	1	0	1	0	0	9
Caregiver/former care	8	7	5	5	5	1	4	0	1	36
Allied health prof'l	1	2	3	2	1	0	1	0	0	10
Neurosurgeon	2	1	2	2	3	0	0	0	0	10
Patient/survivor	4	4	5	2	3	0	4	0	0	22
Nurse	7	7	9	2	3	1	1	1	0	31
Medical oncologist	1	2	1	0	2	0	1	0	0	7
Other health worker	0	1	1	0	0	0	0	0	0	2
Radiation oncologist	1	0	0	0	0	0	0	0	1	2
Interested member of the public	1	0	1	0	0	0	0	0	0	2
Totals	30	24	28	14	18	2	12	1	2	131

Respondents such as social workers have been subsumed in “allied health professional”.

Three people responded to the question asking if they were a brain tumour care coordinator or knew of one. From those responses we were able to cross check names and locations and convey invitations to nominated care coordinators who had not been reached by the initial distribution of the survey. From that information we believe that there are brain tumour care coordinators who spend either all or almost all of their working hours in this role (even if it might only be one day per week) at the following locations/services in Australia:

NSW: Northern Cancer Institute; Liverpool Hospital; Sydney Children’s Hospital, Randwick (Paediatric); South Eastern Sydney and Illawarra Area Health Service – Prince of Wales Hospital (Adults)

Victoria: Southern Health, Clayton; Austin Health; Royal Children’s Hospital (Paediatric); Peter MacCallum Cancer Centre.

Queensland: BrizBrain and Spine; Princess Alexandra Hospital.

WA: WA Cancer and Palliative Care Network - Sir Charles Gairdner Hospital.

(There is also a 0.5FTE nurse on the NSW Central Coast but we understand that her work covers both neurological and urological cancers. As will be seen from the responses that follow there are some other situations where the brain tumour care coordinator role is combined with another responsibility. In the Southern Health (Victoria) position listed above we understand that it is also combined with a palliative care function.)

Unless otherwise indicated all positions are located in the adult treatment environment.

Eleven positions, of which two are for paediatric patients, is not a large number for a country of Australia's size and population which, in 2005, saw 1422 people* diagnosed with a primary malignant brain tumour.

The breast cancer organisations have led the way in the creation of additional care coordinator positions, in addition to the existing, well established dedicated breast cancer nurses. For example, the [McGrath Foundation](#) has funded at least 55 breast care nurses who have supported 4,500 newly diagnosed families. This is in addition to the breast care nurses who have been supported by State/Territory governments and other organisations.

Full information on the number of specific cancer nurses/care coordinators is unknown to BTAA but would be available from the Department of Health and Ageing.

As an example there are 2 – 3 breast cancer nurses in the ACT, plus an additional breast cancer nurse provided through funding through the Jane McGrath Foundation.

In the ACT there are no brain tumour nurses/care coordinators for brain tumours. Support is provided for all cancer patients through limited social worker (1 -2) support from The Canberra Hospital.

BTAA's full report is available on the home page of www.btaa.org.au"

Questions about the report should be directed to secretary@btaa.org.au

Statistical appendix

Table 7. Number of new cases and deaths for Brain and other CNS, persons, Australia, 2007

	Incidence			Mortality		
	Males	Females	Persons	Males	Females	Persons
Number						
2007	901	571	1,472	666	457	1,123
2010 (estimated) ^(a)	930	660	1,600	730	530	1,300
Age-standardised rate^(b)						
2007	8.6	5.0	6.7	6.3	3.9	5.1
<i>CI (95%)</i>	<i>8.0–9.1</i>	<i>4.6–5.4</i>	<i>6.4–7.1</i>	<i>5.8–6.8</i>	<i>3.6–4.3</i>	<i>4.8–5.4</i>
2010 (estimated) ^(a)	8	6	7	6	4	5
Other information for 2007						
% of all cancer	1.5	1.2	1.4	3.0	2.6	2.8
Risk to age 75 years	1 in 146	1 in 255	1 in 186	1 in 197	1 in 313	1 in 243
Risk to age 85 years	1 in 101	1 in 172	1 in 129	1 in 128	1 in 205	1 in 160
Mean age	57.0	58.0	57.4	60.9	63.5	62.0

Source: AIHW Australian Cancer Database; AIHW National Mortality Database

Table 8. New cases and deaths, selected cancers, 2004

	Incidence			Mortality		
	Number	ASR ^(a)	95% CI	Number	ASR ^(a)	95% CI
Brain (C71)	1,472	6.7	6.4–7.1	1,123	5.1	4.8–5.4
Other central nervous system (C70, C72)	78	0.4	0.3–0.4	18	0.1	0.0–0.1

(a) The rates were age-standardised to the Australian population as at 30 June 2001 and expressed by 100,000 population.

(b) For incidence data, those C44 codes that indicate basal or squamous cell carcinoma of the skin are not included.

(c) For mortality data, the applicable codes are C77–C80.

(d) Of relevance for mortality data only.

(e) Includes C97 for mortality data.

Source: AIHW Australian Cancer Database; AIHW National Mortality Database.

Table 9. Underlying cause of death, malignant and benign neoplasms, Australia 2008

Cancer site/type (ICD-10 codes)	New cases			Deaths		
	Males	Females	Persons	Males	Females	Persons
All cancers (C00–C97(a), D45–D47(b))	54,870	43,466	98,336	21,419	16,710	38,129
Head and neck (C01–C14, C30–C32)	1,830	687	2,517	660	218	878
Stomach (C16)	1,275	671	1,946	720	425	1,145
Colon (C18)	4,379	4,167	8,546	1,447	1,342	2,789
Rectum (C19–C20)	2,781	1,650	4,431	749	530	1,279
Colorectal (C18–C20)	7,160	5,817	12,977	2,196	1,872	4,068
Pancreas (C25)	1,003	1,072	2,075	1,013	985	1,998
Lung (C33–C34)	5,826	3,270	9,096	4,733	2,526	7,259
Melanoma of skin (C43)	5,503	4,219	9,722	815	385	1,200
Breast (C50)	109	12,126	12,235	19	2,664	2,683
Cervix (C53)	..	718	718	..	210	210
Uterus, body (C54)	..	1,718	1,718	..	202	202
Ovary (C56)	..	1,246	1,246	..	851	851
Gynaecological (C51–C58)	..	4,144	4,144	..	1,486	1,486
Prostate (C61)	15,759	..	15,759	2,792	..	2,792
Testis (C62)	675	..	675	14	..	14
Kidney (C64)	1,395	822	2,217	497	354	851
Bladder (C67)	1,642	558	2,200	589	314	903
Brain (C71)	799	570	1,369	637	443	1,080
Thyroid (C73)	373	1,128	1,501	42	51	93
Hodgkin lymphoma (C81)	244	233	477	45	26	71
Non-Hodgkin lymphoma (C82C85, C96)	2,108	1,687	3,795	758	710	1,468
Leukaemia (C91–C95)	1,578	1,087	2,665	833	612	1,445
Unknown primary site(c)	1,700	1,592	3,292	1,781	1,741	3,522

(a) Excluding non-melanocytic skin cancer (ICD-10 code C44).

(b) Only includes D47.1 and D47.3.

(c) For mortality, cancer of unknown primary site is coded C26, C39, C76–C80.

Sources: National Cancer Statistics Clearing House and National Mortality Database, AIHW.

Table 10. Causes of death for malignant and benign CNS neoplasms, Australia

Cause of death and ICD-10 code for CNS neoplasms	Number			Standardised Death Rate(e)			Years of potential life lost (f)		
	Males	Females	Persons	Males	Females	Persons	Males	Females	Persons
Australia									
Malignant neoplasm of meninges (C70)	2	10	13	0.0	0.1	0.1	80	104	186
Malignant neoplasm of brain (C71)	710	484	1,194	6.6	4.1	5.3	11,805	7,423	19,164
Malignant neoplasm of spinal cord, cranial nerves and other parts of central nervous system (C72)	3	5	9	0.0	0.0	0.0	117	70	187
Benign neoplasm of meninges (D32)	30	47	77	0.3	0.4	0.3	57	289	349
Benign neoplasm of brain and other parts of central nervous system (D33)	5	2	8	0.0	0.0	0.0	134	21	158
Neoplasm of uncertain or unknown behaviour of meninges (D42)	4	0	2	0.0	0.0	0.0	6	0	6
Neoplasm of uncertain or unknown behaviour of brain and central nervous system (D43)	74	82	156	0.7	0.6	0.7	885	581	1,465
Total Australia	828	630	1,459	7.6	5.2	6.4	13,084	8,487	21,513

(a) 2008 data have been subject to process improvements which have increased the quality of these data. See ABS Cat. No. 3303.0 Technical Note 1: 2008 COD Collection - Process Improvements for further information. (b) Causes of death data for 2008 are preliminary and subject to a revisions process. See ABS Cat. No. 3303.0 Technical Note 2: Causes of Death - Revisions Process. (c) Data cells with small values have been randomly assigned to protect the confidentiality of individuals. As a result, some totals will not equal the sum of their components. Cells with a zero value have not been affected by confidentialisation. (d) See ABS Cat. No. 3303.0 Explanatory Notes 63-76 for further information on specific issues relating to 2008 data. (e) See ABS Cat. No. 3303.0 Glossary for further information. (f) See ABS Cat. No. 3303.0 Explanatory Notes 43-45 for further information on Years of potential life lost.

Table 11. Causes of death for malignant and benign CNS neoplasms, States and Territories

Source: Australian Bureau of Statistics (ABS), *Causes of Death, Australia, 2008* (ABS Cat. no. 3303.0)

Cause of death and ICD-10 code for CNS neoplasms	Number			Standardised Death Rate(e)			Years of potential life lost (f)		
	Males	Females	Persons	Males	Females	Persons	Males	Females	Persons
New South Wales									
Malignant neoplasm of meninges (C70)	0	2	1	0.0	0.1	0.0	0	14	14
Malignant neoplasm of brain (C71)	202	163	365	5.7	4.1	4.9	3,342	2,440	5,768
Malignant neoplasm of spinal cord, cranial nerves and other parts of central nervous system (C72)	0	0	0	0.0	0.0	0.0	0	0	0
Benign neoplasm of meninges (D32)	15	18	33	0.5	0.4	0.4	25	131	157
Benign neoplasm of brain and other parts of central nervous system (D33)	0	2	4	0.0	0.0	0.0	0	0	0
Neoplasm of uncertain or unknown behaviour of meninges (D42)	0	0	0	0.0	0.0	0.0	0	0	0
Neoplasm of uncertain or unknown behaviour of brain and central nervous system (D43)	35	32	67	1.0	0.7	0.8	436	121	559
Total New South Wales	252	217	470	7.2	5.3	6.1	3,804	2,706	6,498
Victoria									
Malignant neoplasm of meninges (C70)	2	2	1	0.1	0.0	0.1	4	0	4
Malignant neoplasm of brain (C71)	189	121	310	7.0	4.1	5.5	3,047	1,980	4,997
Malignant neoplasm of spinal cord, cranial nerves and other parts of central nervous system (C72)	3	3	3	0.0	0.0	0.0	0	19	19
Benign neoplasm of meninges (D32)	7	9	16	0.3	0.3	0.3	16	46	63
Benign neoplasm of brain and other parts of central nervous system (D33)	3	2	6	0.1	0.1	0.1	68	21	91
Neoplasm of uncertain or unknown behaviour of meninges (D42)	4	0	2	0.0	0.0	0.0	6	0	6
Neoplasm of uncertain or unknown behaviour of brain and central nervous system (D43)	16	19	35	0.7	0.5	0.6	144	164	308
Total Victoria	224	156	373	8.2	5.0	6.6	3,285	2,230	5,488
Queensland									
Malignant neoplasm of meninges (C70)	0	2	1	0.0	0.0	0.0	0	27	27
Malignant neoplasm of brain (C71)	146	91	237	6.8	4.1	5.4	2,636	1,341	3,965
Malignant neoplasm of spinal cord, cranial nerves and other parts of central nervous system (C72)	3	3	3	0.0	0.1	0.1	27	9	36
Benign neoplasm of meninges (D32)	6	8	14	0.3	0.3	0.3	16	45	61
Benign neoplasm of brain and other parts of central nervous system (D33)	3	0	4	0.0	0.0	0.0	61	0	63
Neoplasm of uncertain or unknown behaviour of meninges (D42)	0	0	0	0.0	0.0	0.0	0	0	0
Neoplasm of uncertain or unknown behaviour of brain and central nervous system (D43)	14	13	27	0.7	0.6	0.7	223	125	348
Queensland	172	117	286	7.8	5.1	6.5	2,963	1,547	4,500
South Australia									
Malignant neoplasm of meninges (C70)	2	0	1	0.1	0.0	0.1	78	0	80
Malignant neoplasm of brain (C71)	69	34	103	7.9	3.6	5.6	1,014	612	1,617
Malignant neoplasm of spinal cord, cranial nerves and other parts of central nervous system (C72)	0	0	0	0.0	0.0	0.0	0	0	0
Benign neoplasm of meninges (D32)	2	1	5	0.2	0.3	0.2	0	36	37
Benign neoplasm of brain and other parts of central nervous system (D33)	0	0	0	0.0	0.0	0.0	0	0	0
Neoplasm of uncertain or unknown behaviour of meninges (D42)	0	0	0	0.0	0.0	0.0	0	0	0
Neoplasm of uncertain or unknown behaviour of brain and central nervous system (D43)	5	11	16	0.5	1.0	0.8	38	54	92
Total South Australia	78	46	125	8.7	4.9	6.7	1,129	702	1,826

Cause of death and ICD-10 code for CNS neoplasms	Number			Standardised Death Rate(e)			Years of potential life lost (f)		
	Males	Females	Persons	Males	Females	Persons	Males	Females	Persons
Western Australia									
Malignant neoplasm of meninges (C70)	0	2	1	0.0	0.2	0.1	0	39	39
Malignant neoplasm of brain (C71)	71	44	115	6.6	3.9	5.3	1,208	502	1,704
Malignant neoplasm of spinal cord, cranial nerves and other parts of central nervous system (C72)	3	3	3	0.1	0.1	0.1	54	41	95
Benign neoplasm of meninges (D32)	0	6	6	0.0	0.6	0.3	0	18	18
Benign neoplasm of brain and other parts of central nervous system (D33)	0	0	0	0.0	0.0	0.0	0	0	0
Neoplasm of uncertain or unknown behaviour of meninges (D42)	0	0	0	0.0	0.0	0.0	0	0	0
Neoplasm of uncertain or unknown behaviour of brain and central nervous system (D43)	1	5	7	0.2	0.4	0.3	29	17	45
Total Western Australia	75	60	132	6.9	5.2	6.1	1,290	616	1,901
Tasmania									
Malignant neoplasm of meninges (C70)	0	0	0	0.0	0.0	0.0	0	0	0
Malignant neoplasm of brain (C71)	24	19	43	9.0	6.1	7.5	358	223	576
Malignant neoplasm of spinal cord, cranial nerves and other parts of central nervous system (C72)	3	0	3	0.5	0.0	0.2	39	0	39
Benign neoplasm of meninges (D32)	0	1	4	0.0	0.3	0.2	0	0	0
Benign neoplasm of brain and other parts of central nervous system (D33)	0	0	0	0.0	0.0	0.0	0	0	0
Neoplasm of uncertain or unknown behaviour of meninges (D42)	0	0	0	0.0	0.0	0.0	0	0	0
Neoplasm of uncertain or unknown behaviour of brain and central nervous system (D43)	1	2	1	0.7	0.3	0.5	9	12	21
Total Tasmania	28	22	51	10.2	6.7	8.4	407	235	636
Northern Territory									
Malignant neoplasm of meninges (C70)	0	0	0	0.0	0.0	0.0	0	0	0
Malignant neoplasm of brain (C71)	3	2	2	0.8	1.8	1.3	66	89	150
Malignant neoplasm of spinal cord, cranial nerves and other parts of central nervous system (C72)	0	0	0	0.0	0.0	0.0	0	0	0
Benign neoplasm of meninges (D32)	0	0	0	0.0	0.0	0.0	0	0	0
Benign neoplasm of brain and other parts of central nervous system (D33)	0	0	0	0.0	0.0	0.0	0	0	0
Neoplasm of uncertain or unknown behaviour of meninges (D42)	0	0	0	0.0	0.0	0.0	0	0	0
Neoplasm of uncertain or unknown behaviour of brain and central nervous system (D43)	0	0	0	0.0	0.0	0.0	0	0	0
Total Northern Territory	3	2	2	0.8	1.8	1.3	66	89	150
Australian Capital Territory									
Malignant neoplasm of meninges (C70)	0	2	1	0.0	1.2	0.6	0	26	27
Malignant neoplasm of brain (C71)	8	10	18	6.0	6.3	5.9	81	225	305
Malignant neoplasm of spinal cord, cranial nerves and other parts of central nervous system (C72)	0	0	0	0.0	0.0	0.0	0	0	0
Benign neoplasm of meninges (D32)	0	1	4	0.0	0.8	0.4	0	6	7
Benign neoplasm of brain and other parts of central nervous system (D33)	0	0	0	0.0	0.0	0.0	0	0	0
Neoplasm of uncertain or unknown behaviour of meninges (D42)	0	0	0	0.0	0.0	0.0	0	0	0
Neoplasm of uncertain or unknown behaviour of brain and central nervous system (D43)	0	2	1	0.0	0.6	0.3	0	84	82
Total Australian Capital Territory	8	15	24	6.0	8.9	7.2	81	342	421

(a) 2008 data have been subject to process improvements which have increased the quality of these data. See ABS Cat. No. 3303.0 Technical Note 1: 2008 COD Collection - Process Improvements for further information. (b) Causes of death data for 2008 are preliminary and subject to a revisions process. See ABS Cat. No. 3303.0 Technical Note 2: Causes of Death - Revisions Process. (c) Data cells with small values have been randomly assigned to protect the confidentiality of individuals. As a result, some totals will not equal the sum of their components. Cells with a zero value have not been affected by confidentialisation. (d) See ABS Cat. No. 3303.0 Explanatory Notes 63-76 for further information on specific issues relating to 2008 data. (e) See ABS Cat. No. 3303.0 Glossary for further information. (f) See ABS Cat. No. 3303.0 Explanatory Notes 43-45 for further information on Years of potential life lost.

Table 11. One, five and ten-year relative survival by cancer site, diagnoses in 1998–2004

Cancer site/type (ICD-10)	1-year survival (%)			5-year survival (%)			10-year survival (%) ^(a)		
	Males	Females	Persons	Males	Females	Persons	Males	Females	Persons
All cancers (C00–C96(b), D45–D47(c))	74.9	78.7	76.6	58.4	64.1	61.0	51.6	58.1	54.6
Head and neck (C01–C14, C30–C32)	80.3	80.8	80.4	55.0	59.9	56.3	43.8	51.7	46.0
Stomach (C16)	49.2	48.0	48.8	24.4	25.3	24.7	20.5	22.0	21.1
Colon (C18)	79.1	78.0	78.6	60.9	61.6	61.3	54.9	56.7	55.8
Rectum (C19–C20)	84.5	84.5	84.5	61.9	64.5	62.9	55.2	58.0	56.3
Colorectal (C18–C20)	81.2	80.0	80.7	61.3	62.4	61.8	55.1	57.1	56.0
Pancreas (C25)	19.1	19.1	19.1	4.5	4.7	4.6	3.9	3.6	3.7
Lung (C33–C34)	33.6	38.8	35.4	10.7	14.0	11.8	7.6	10.1	8.4
Melanoma of skin (C43)	97.0	98.4	97.6	89.7	94.1	91.6	86.5	92.0	89.0
Breast (C50)	95.8	97.2	97.2	82.0	87.8	87.7	67.2	79.5	79.4
Cervix (C53)	..	87.2	71.8	68.0	..
Uterus, body (C54)	..	92.6	82.1	78.9	..
Ovary (C56)	..	73.2	39.8	31.7	..
Gynaecological (C51–C58)	..	84.8	65.3	60.0	..
Prostate (C61)	95.5	85.3	75.4
Testis (C62)	98.6	96.8	95.8
Kidney (C64)	80.2	77.9	79.3	65.6	66.0	65.8	57.2	58.3	57.6
Bladder (C67)	82.8	73.0	80.3	62.3	54.8	60.4	55.3	48.7	53.7
Brain (C71)	42.5	38.7	40.9	18.5	19.4	18.9	14.7	15.7	15.1
Thyroid (C73)	92.5	96.9	95.8	87.7	95.3	93.4	84.2	94.5	91.9
Hodgkin lymphoma (C81)	92.1	93.3	92.6	84.8	85.8	85.2	78.9	83.0	80.7
Non-Hodgkin lymphoma (C82–C85, C96)	78.1	77.5	77.9	61.6	62.6	62.1	51.6	51.6	51.6
Leukaemia (C91–C95)	68.2	65.7	67.1	48.2	47.3	47.8	36.8	39.2	37.9
Unknown primary site (C26, C39, C76, C80)	18.6	15.8	17.2	10.6	7.6	9.1	8.1	5.7	6.9

(a) 10-year relative survival proportions are based on 1996–2004 diagnoses.

(b) Excluding non-melanocytic skin cancer (ICD-10 code C44).

(c) Only includes D47.1 and D47.3.

Source: National Cancer Statistics Clearing House, AIHW.

Table 12. Trends in 5-year relative survival by cancer site, diagnoses from 1982–1986 to 1998–2004

Cancer site/type (ICD-10 codes)	1982–1986		1987–1991		1992–1997		1998–2004	
	per cent	95 per cent CI	per cent	95 per cent CI	per cent	95 per cent CI	per cent	95 per cent CI
All cancers (C00–C96(a), D45–D47(b))	41.3	41.0–41.6	45.9	45.6–46.2	54.8	54.6–55.1	58.4	58.2–58.6
Stomach (C16)	16.2	15.2–17.3	18.9	17.9–20.0	20.5	19.5–21.5	24.4	23.3–25.4
Colon (C18)	48.3	47.2–49.4	53.2	52.2–54.1	57.0	56.1–57.8	60.9	60.2–61.7
Rectum (C19–C20)	46.8	45.4–48.2	50.1	48.8–51.3	56.5	55.5–57.5	61.9	61.0–62.8
Colorectal (C18–C20)	47.7	46.9–48.6	52.0	51.2–52.8	56.8	56.2–57.4	61.3	60.7–61.9
Pancreas (C25)	2.8	2.3–3.3	3.0	2.5–3.5	4.2	3.7–4.8	4.5	4.0–5.0
Lung (C33–C34)	7.9	7.5–8.2	9.1	8.7–9.4	9.7	9.3–10.0	10.7	10.3–11.0
Melanoma of skin (C43)	82.2	81.3–83.2	86.3	85.6–87.1	89.3	88.7–89.8	89.7	89.1–90.2
Prostate (C61)	57.4	56.4–58.4	63.2	62.4–64.0	81.7	81.2–82.1	85.3	84.9–85.7
Testis (C62)	90.8	89.2–92.2	95.0	93.8–96.1	95.3	94.4–96.1	96.8	96.0–97.4
Kidney (C64)	45.2	43.1–47.2	49.8	48.0–51.7	58.6	57.1–60.0	65.6	64.4–66.8
Bladder (C67)	69.1	67.7–70.4	69.1	67.7–70.5	65.2	63.9–66.4	62.3	61.1–63.5
Brain (C71)	20.8	19.3–22.4	19.7	18.3–21.2	18.7	17.5–19.9	18.5	17.5–19.6
Thyroid (C73)	79.1	74.9–82.8	78.3	74.5–81.7	85.3	82.7–87.6	87.7	85.8–89.5
Hodgkin lymphoma (C81)	72.0	68.8–75.0	76.8	73.8–79.6	81.5	79.0–83.8	84.8	82.7–86.7
Non-Hodgkin lymphoma (C82–C85, C96)	46.3	44.7–47.9	48.2	46.8–49.6	52.3	51.2–53.5	61.6	60.6–62.6
Leukaemia (C91–C95)	37.9	36.4–39.5	42.6	41.1–44.1	43.0	41.7–44.2	48.2	47.0–49.3
Unknown primary site (C26, C39, C76, C80)	6.4	5.9–7.0	6.9	6.4–7.5	6.7	6.3–7.1	10.6	10.1–11.2
All cancers (C00–C96(a), D45–D47(b))	53.2	52.9–53.5	57.1	56.8–57.4	60.8	60.6–61.0	64.1	63.9–64.3
Stomach (C16)	18.2	16.8–19.6	18.9	17.5–20.4	22.3	20.9–23.7	25.3	23.9–26.7
Colon (C18)	49.5	48.4–50.5	52.9	51.9–53.8	56.5	55.7–57.3	61.6	60.8–62.3
Rectum (C19–C20)	50.4	48.9–52.0	54.0	52.5–55.5	59.4	58.2–60.6	64.5	63.4–65.6
Colorectal (C18–C20)	49.7	48.9–50.6	53.2	52.4–54.0	57.4	56.7–58.1	62.4	61.8–63.1
Pancreas (C25)	2.8	2.3–3.4	4.0	3.4–4.7	3.5	3.0–4.0	4.7	4.2–5.3
Lung (C33–C34)	10.5	9.8–11.3	10.8	10.2–11.5	12.6	12.0–13.2	14.0	13.4–14.5
Melanoma of skin (C43)	90.5	89.7–91.2	92.8	92.2–93.4	93.9	93.4–94.4	94.1	93.6–94.6
Breast (C50)	71.8	71.1–72.4	77.5	77.0–78.0	83.7	83.3–84.1	87.8	87.5–88.1
Cervix (C53)	68.3	66.9–69.7	71.2	69.9–72.5	73.6	72.4–74.8	71.8	70.4–73.1
Uterus, body (C54)	75.6	74.1–77.1	78.0	76.6–79.4	80.2	79.1–81.3	82.1	81.1–83.0
Ovary (C56)	32.7	31.3–34.2	35.7	34.3–37.1	37.9	36.6–39.1	39.8	38.6–41.0
Kidney (C64)	48.8	46.2–51.5	52.5	50.2–54.8	58.7	56.8–60.5	66.0	64.4–67.5
Bladder (C67)	65.0	62.8–67.1	61.9	59.7–64.1	55.8	53.7–57.9	54.8	52.9–56.7
Brain (C71)	19.9	18.2–21.6	20.4	18.8–22.0	18.3	17.0–19.7	19.4	18.1–20.6
Thyroid (C73)	85.3	83.1–87.2	89.9	88.2–91.5	94.3	93.3–95.3	95.3	94.5–96.0
Hodgkin lymphoma (C81)	71.3	67.5–74.8	77.5	74.1–80.6	83.6	81.0–86.0	85.8	83.5–87.8
Non-Hodgkin lymphoma (C82–C85, C96)	47.6	45.9–49.3	52.4	50.9–54.0	54.0	52.7–55.2	62.6	61.5–63.6
Leukaemia (C91–C95)	37.2	35.4–39.0	42.9	41.2–44.6	42.8	41.4–44.3	47.3	46.0–48.6
Unknown primary site (C26, C39, C76, C80)	5.6	5.1–6.2	5.9	5.4–6.4	5.5	5.1–6.0	7.6	7.1–8.0

(continued)

Table 12 (continued). Trends in 5-year relative survival by cancer site, diagnoses from 1982–1986 to 1998–2004

Cancer site/type (ICD-10)	1982–1986		1987–1991		1992–1997		1998–2004	
	%	95 per cent	%	95 per cent	%	95 per cent	%	95 per cent
All cancers (C00–C96(a), D45–D47(b))	46.9	46.7–47.1	51.2	51.0–51.4	57.5	57.4–57.7	61.0	60.9–61.2
Stomach (C16)	16.9	16.1–17.8	18.9	18.1–19.8	21.2	20.3–22.0	24.7	23.9–25.6
Colon (C18)	48.9	48.2–49.6	53.0	52.3–53.7	56.7	56.2–57.3	61.3	60.7–61.8
Rectum (C19–C20)	48.4	47.3–49.4	51.7	50.7–52.6	57.7	56.9–58.5	62.9	62.2–63.6
Colorectal (C18–C20)	48.7	48.1–49.3	52.6	52.0–53.1	57.1	56.6–57.5	61.8	61.4–62.3
Pancreas (C25)	2.8	2.4–3.2	3.5	3.1–3.9	3.8	3.5–4.2	4.6	4.2–5.0
Lung (C33–C34)	8.5	8.2–8.8	9.5	9.2–9.8	10.6	10.3–10.9	11.8	11.5–12.1
Melanoma of skin (C43)	86.5	85.8–87.1	89.4	88.9–89.9	91.4	91.0–91.8	91.6	91.3–92.0
Kidney (C64)	46.5	44.9–48.2	50.8	49.4–52.3	58.6	57.5–59.8	65.8	64.8–66.7
Bladder (C67)	68.0	66.8–69.2	67.3	66.1–68.4	62.9	61.8–63.9	60.4	59.4–61.4
Brain (C71)	20.4	19.3–21.6	20.0	19.0–21.1	18.6	17.7–19.5	18.9	18.1–19.7
Thyroid (C73)	83.6	81.7–85.4	86.8	85.2–88.3	92.1	91.1–93.0	93.4	92.7–94.1
Hodgkin lymphoma (C81)	71.7	69.3–74.0	77.1	74.9–79.2	82.5	80.7–84.2	85.2	83.7–86.6
Non-Hodgkin lymphoma (C82–C85, C96)	46.9	45.7–48.1	50.1	49.1–51.2	53.1	52.2–53.9	62.1	61.3–62.8
Leukaemia (C91–C95)	37.6	36.4–38.8	42.7	41.6–43.8	42.9	42.0–43.9	47.8	47.0–48.7
Unknown primary site (C26, C39, C76, C80)	6.0	5.7–6.4	6.5	6.1–6.8	6.1	5.8–6.4	9.1	8.8–9.5

(a) Excluding non-melanocytic skin cancer (ICD-10 code C44).

(b) Only includes D47.1 and D47.3. Source: National Cancer Statistics Clearing House, AIHW.

Table 12 (continued). Trends in cancer relative survival of children, all cancers, bone, brain, leukaemia diagnoses from 1982–1986 to 1998–2004

Cancer site/type (ICD-10 codes)	1982–1986		1987–1991		1992–1997		1998–2004	
	%	95 per cent CI	%	95 per cent CI	%	95 per cent CI	%	95 per cent CI
All cancers (C00–C96(a), D45–D47(b))								
1-year survival	84.1	82.5–85.5	87.2	85.8–88.4	87.8	86.6–88.8	89.5	88.5–90.4
5-year survival	66.5	64.6–68.4	72.7	70.9–74.4	73.2	71.6–74.7	78.5	77.1–79.8
10-year survival(c)	62.6	60.6–64.5	69.8	68.0–71.6	70.5	68.9–72.0	75.8	74.4–77.1
Bone and connective tissue (C40–C41, C47–C49)								
1-year survival	86.2	81.4–89.8	91.1	86.8–94.1	91.9	88.5–94.3	91.4	88.4–93.7
5-year survival	62.9	56.8–68.3	71.1	65.0–76.3	71.6	66.7–75.9	69.9	65.1–74.1
10-year survival(c)	59.3	53.2–64.9	66.7	60.4–72.3	69.0	64.0–73.5	67.2	62.6–71.3
Brain and central nervous system (C70–C72)								
1-year survival	75.1	71.0–78.8	76.7	72.5–80.4	71.9	68.0–75.5	72.4	68.8–75.7
5-year survival	57.5	52.9–61.8	60.2	55.5–64.6	56.5	52.3–60.5	56.2	52.1–60.0
10-year survival(c)	52.8	48.2–57.2	57.4	52.6–61.8	52.2	48.0–56.3	53.1	49.2–56.7
Leukaemia (C91–C95)								
1-year survival	86.4	83.8–88.5	89.4	87.2–91.3	89.7	87.7–91.3	92.4	90.9–93.7
5-year survival	64.2	60.8–67.4	71.6	68.5–74.4	71.8	69.0–74.4	82.6	80.4–84.5
10-year survival(c)	58.8	55.4–62.1	67.8	64.6–70.7	68.3	65.5–71.0	78.6	76.3–80.7

(a) Excluding non-melanocytic skin cancer (ICD-10 code C44).

(b) Only includes D47.1 and D47.3.

(c) 10-year relative survival proportions for the most recent period are based on 1996–2004 diagnoses.

Source: National Cancer Statistics Clearing House, AIHW.

Media release

[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 O’Brien, 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

BTAA Resources

[The Primer of Brain Tumors](#), published by the American Brain Tumor Association (ABTA) and can be downloaded chapter by chapter (BTAA can also send you a printed copy of the Primer)

A Fact Sheet on brain tumours and depression and anxiety disorders co-released by Beyond Blue and BTAA: Go to: www.beyondblue.org.au > Get information > Download information materials and click on Depression and chronic physical illness > Fact sheet 46 Brain tumours, depression and anxiety disorders.

[Fact Sheets and Resource Sheets](#) for brain tumour patients, family and caregivers, developed by the Cancer Institute NSW NSWOG Neuro-Oncology group, and the booklet [Understanding Brain Tumours](#), developed by the Cancer Council NSW.

Freecall: 1800 857 221

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