



**Brain Tumour Alliance Australia Inc**  
**Submission to the 2011–12 Federal Budget**  
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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](http://www.btaa.org.au)

During 2010 BTAA partnered with *beyondblue* to [produce a fact sheet for people living with brain tumours on depression and anxiety](#), launched by Ms Leonie Young, CEO of *beyondblue* 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.au](http://www.btaa.org.au)

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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, 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 5<sup>th</sup> in terms of life years lost from disease<sup>1</sup>. (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).

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<sup>1</sup> 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 a 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 so-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](http://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 work load. They reported 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 females<sup>2</sup>.

Brain tumour patients had the second longest average (hospital) length of stay (12.5 days) in 2008-09.<sup>3</sup>

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.<sup>4</sup> 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. CSN (including brain tumour and other central nervous system) health policy:

- **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;

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<sup>2</sup> Cancer in Australia, An overview , AIHW, 2010, pg 61

<sup>3</sup> Ibid, pg 68

<sup>4</sup> 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 subspecialisation 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. This is in contrast with tumours in other parts of the body that may be invasive but grow more slowly.
- 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 tumours than women but more women develop meningioma (benign) brain tumours.
- 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 – 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 (f) |              |               |
|---|------------|------------|--------------|----------------------------------|--------------|---------------|
|   | Males      | Females    | Persons      | Males                            | Females      | Persons       |
| <b>Australia</b>  |            |            |              |                                  |              |               |
| 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 central nervous system (C72) | 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 system (D43)              | 74         | 82         | 156          | 885                              | 581          | 1,465         |
| <b>Total Australia</b>  | <b>828</b> | <b>630</b> | <b>1,459</b> | <b>13,084</b>                    | <b>8,487</b> | <b>21,513</b> |

(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.

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**

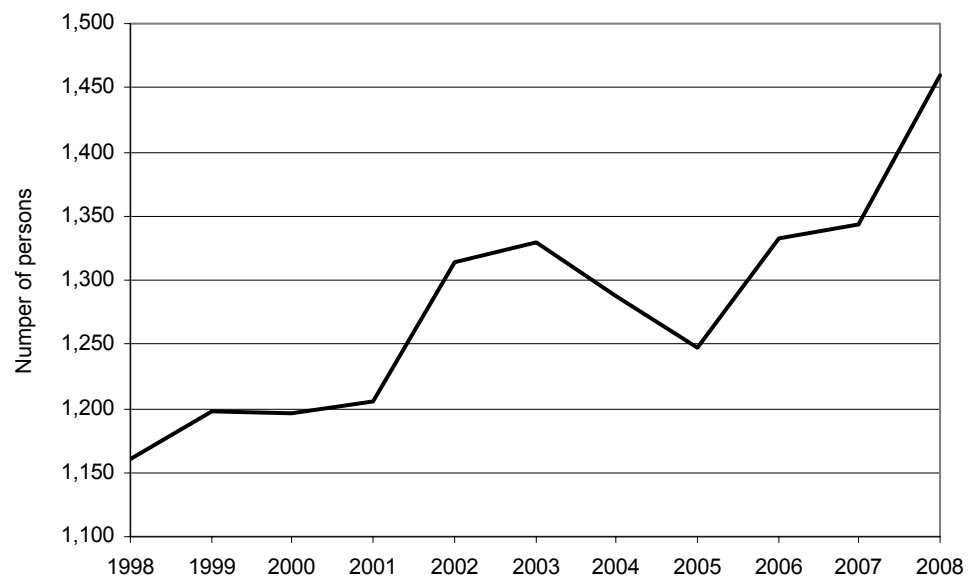
| Cause of death and ICD-10 code for CNS neoplasms | Number     |            |              | Years of potential life lost (f) |              |               |
|--|------------|------------|--------------|----------------------------------|--------------|---------------|
|  | Males      | Females   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

(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.

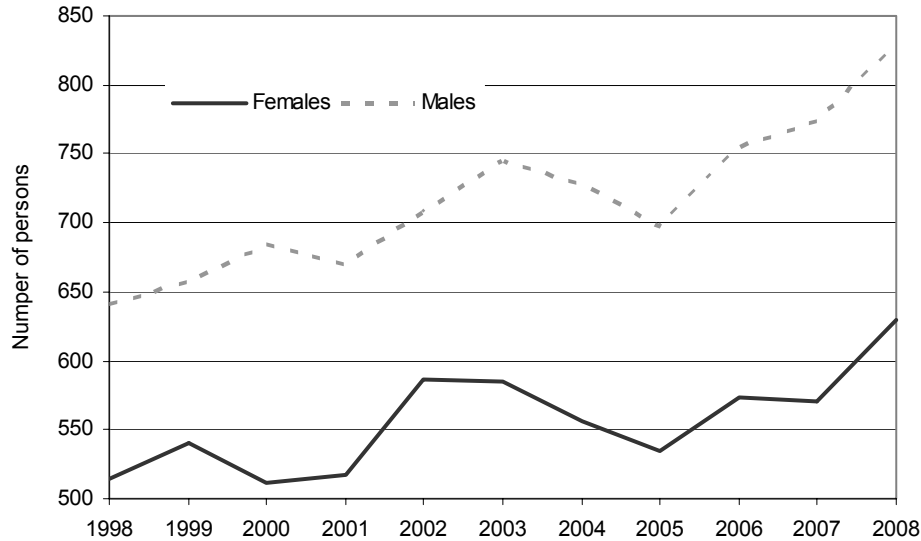
(b) Causes of death data for 2008 are preliminary and subject to a revisions process. See ABS Cat. No. 3303.0 Technical Note 2: Causes of Death - Revisions Process.

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.

**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).

(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.

## Survival trends<sup>i</sup>

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 neither adults nor children with brain tumours.

- 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).
- Cancers with the lowest 5-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).
- For both males and females, brain cancer showed no significant change in survival between 1982–1986 and 1998–2004.
- The 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).
- For males, one-year relative survival was highest for testicular cancer (99 per cent) and lowest for cancer of unknown primary site (19 per cent). At both 5 and 10 years after diagnosis, relative survival was highest for testicular cancer (97 per cent at 5 years, 96 per cent at 10 years) and lowest for pancreatic cancer (4.5 per cent at 5 years, 3.9 per cent at 10 years).
- For females, one-year relative survival was highest for melanoma of the skin (98 per cent) and lowest for cancer of unknown primary site (16 per cent). At both five and 10 years after diagnosis, relative survival was highest for thyroid cancer (95 per cent at both five and 10 years) and lowest for pancreatic cancer (4.7 per cent at five years, 3.6 per cent at 10 years).

## Children and teenagers

- Cancer survival for children aged 0–14 years was high, with an all-cancer 5-year relative survival of 79 per cent for children diagnosed in 1998–2004. Relative survival for children at 1, 5 and 10 years after diagnosis was much higher than for Australians aged 65 and over.
- However for children aged 0–14 years, survival from cancers of **the brain and central nervous** system and of bone and connective tissue showed no significant increase between 1982–1986 and 1998–2004.
- 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 those facing this terrible diagnosis.
- 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 high, with an all-cancer 5-year relative survival of 79 per cent for children diagnosed in 1998–2004. However, for children aged 0–14 years, survival from **cancers of the brain and central nervous system** and of bone and connective tissue showed no significant increase between 1982–1986 and 1998–2004.



- 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
- For females, the cancers that showed the greatest increase in five-year relative survival were:
  - kidney cancer, which increased from 49 per cent in 1982–1986 to 66 per cent in 1998–2004;
  - breast cancer, which increased from 72 per cent in 1982–1986 to 88 per cent in 1998–2004; and
  - non-Hodgkin lymphoma, which increased from 48 per cent in 1982–1986 to 63 per cent in 1998–2004.

**Table 3 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 |
| <b>2007</b>   |        |         |         |                             |         |         |
| 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     |
| <b>2008</b>   |        |         |         |                             |         |         |
| 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](http://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:

| 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 <sup>1</sup> | 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          |
| <b>Totals</b>                   | <b>30</b> | <b>24</b> | <b>28</b> | <b>14</b> | <b>18</b> | <b>2</b> | <b>12</b> | <b>1</b> | <b>2</b> | <b>131</b> |

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

3 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 .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.

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](http://www.btaa.org.au)

Questions about the report should be directed to [secretary@btaa.org.au](mailto:secretary@btaa.org.au)

# Statistical appendix

**Table 4: Incidence and mortality of brain cancer observed for 2007, and estimated for 2010**

|  | Incidence      |                |                | Mortality      |                |                |
|--|----------------|----------------|----------------|----------------|----------------|----------------|
|  | Males          | Females        | Persons        | Males          | Females        | Persons        |
| <b>Number</b>                              |                |                |                |                |                |                |
| 2007                                       | 901            | 571            | 1,472          | 666            | 457            | 1,123          |
| 2010 (estimated) <sup>(a)</sup>            | 930            | 660            | 1,600          | 730            | 530            | 1,300          |
| <b>Age-standardised rate<sup>(b)</sup></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) <sup>(a)</sup>            | 8              | 6              | 7              | 6              | 4              | 5              |
| <b>Other information for 2007</b>          |                |                |                |                |                |                |
| % 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 5: Number of new cases and deaths for Brain and other CNS, persons, Australia, 2007**

|   | Incidence |                    |         | Mortality |                    |         |
|---|-----------|--------------------|---------|-----------|--------------------|---------|
|   | Number    | ASR <sup>(a)</sup> | 95% CI  | Number    | ASR <sup>(a)</sup> | 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 6: New cases and deaths, selected cancers, 2004**

| Cancer site/type (ICD-10 codes)                     | New cases |         |         | Deaths |         |         |
|---|-----------|---------|---------|--------|---------|---------|
|   | Males     | Females | Persons | Males  | Females | Persons |
| <b>All cancers (C00–C97(a), D45–D47(b))</b>         | 54,870    | 43,466  | 98,336  | 21,419 | 16,710  | 38,129  |
| <b>Head and neck (C01–C14, C30–C32)</b>             | 1,830     | 687     | 2,517   | 660    | 218     | 878     |
| <b>Stomach (C16)</b>                                | 1,275     | 671     | 1,946   | 720    | 425     | 1,145   |
| <b>Colon (C18)</b>                                  | 4,379     | 4,167   | 8,546   | 1,447  | 1,342   | 2,789   |
| <b>Rectum (C19–C20)</b>                             | 2,781     | 1,650   | 4,431   | 749    | 530     | 1,279   |
| <b>Colorectal (C18–C20)</b>                         | 7,160     | 5,817   | 12,977  | 2,196  | 1,872   | 4,068   |
| <b>Pancreas (C25)</b>                               | 1,003     | 1,072   | 2,075   | 1,013  | 985     | 1,998   |
| <b>Lung (C33–C34)</b>                               | 5,826     | 3,270   | 9,096   | 4,733  | 2,526   | 7,259   |
| <b>Melanoma of skin (C43)</b>                       | 5,503     | 4,219   | 9,722   | 815    | 385     | 1,200   |
| <b>Breast (C50)</b>                                 | 109       | 12,126  | 12,235  | 19     | 2,664   | 2,683   |
| <b>Cervix (C53)</b>                                 | ..        | 718     | 718     | ..     | 210     | 210     |
| <b>Uterus, body (C54)</b>                           | ..        | 1,718   | 1,718   | ..     | 202     | 202     |
| <b>Ovary (C56)</b>                                  | ..        | 1,246   | 1,246   | ..     | 851     | 851     |
| <b>Gynaecological (C51–C58)</b>                     | ..        | 4,144   | 4,144   | ..     | 1,486   | 1,486   |
| <b>Prostate (C61)</b>                               | 15,759    | ..      | 15,759  | 2,792  | ..      | 2,792   |
| <b>Testis (C62)</b>                                 | 675       | ..      | 675     | 14     | ..      | 14      |
| <b>Kidney (C64)</b>                                 | 1,395     | 822     | 2,217   | 497    | 354     | 851     |
| <b>Bladder (C67)</b>                                | 1,642     | 558     | 2,200   | 589    | 314     | 903     |
| <b>Brain (C71)</b>                                  | 799       | 570     | 1,369   | 637    | 443     | 1,080   |
| <b>Thyroid (C73)</b>                                | 373       | 1,128   | 1,501   | 42     | 51      | 93      |
| <b>Hodgkin lymphoma (C81)</b>                       | 244       | 233     | 477     | 45     | 26      | 71      |
| <b>Non-Hodgkin lymphoma (C82–C85, C96)</b>          | 2,108     | 1,687   | 3,795   | 758    | 710     | 1,468   |
| <b>Leukaemia (C91–C95)</b>                          | 1,578     | 1,087   | 2,665   | 833    | 612     | 1,445   |
| <b>Unknown primary site (C26, C39, C76, C80)(c)</b> | 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 7: Underlying cause of death, malignant and benign neoplasms, Australia 2008**

| 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       |
| <b>Australia</b>  |            |            |              |                            |            |            |                                  |              |               |
| 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         |
| <b>Total Australia</b>  | <b>828</b> | <b>630</b> | <b>1,459</b> | <b>7.6</b>                 | <b>5.2</b> | <b>6.4</b> | <b>13,084</b>                    | <b>8,487</b> | <b>21,513</b> |

(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 8: Underlying cause of death, malignant and benign neoplasms by States and Territories, 2008**

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      |
| <b>New South Wales</b>  |            |            |            |                            |            |            |                                  |              |              |
| 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          |
| <b>Total New South Wales</b>  | <b>252</b> | <b>217</b> | <b>470</b> | <b>7.2</b>                 | <b>5.3</b> | <b>6.1</b> | <b>3,804</b>                     | <b>2,706</b> | <b>6,498</b> |
| <b>Victoria</b>   |            |            |            |                            |            |            |                                  |              |              |
| 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          |
| <b>Total Victoria</b>   | <b>224</b> | <b>156</b> | <b>373</b> | <b>8.2</b>                 | <b>5.0</b> | <b>6.6</b> | <b>3,285</b>                     | <b>2,230</b> | <b>5,488</b> |
| <b>Queensland</b>   |            |            |            |                            |            |            |                                  |              |              |
| 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          |
| <b>Queensland</b>   | <b>172</b> | <b>117</b> | <b>286</b> | <b>7.8</b>                 | <b>5.1</b> | <b>6.5</b> | <b>2,963</b>                     | <b>1,547</b> | <b>4,500</b> |
| <b>South Australia</b>  |            |            |            |                            |            |            |                                  |              |              |
| 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           |
| <b>Total South Australia</b>  | <b>78</b>  | <b>46</b>  | <b>125</b> | <b>8.7</b>                 | <b>4.9</b> | <b>6.7</b> | <b>1,129</b>                     | <b>702</b>   | <b>1,826</b> |

| 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      |
| <b>Western Australia</b>  |           |           |            |                            |            |            |                                  |            |              |
| 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           |
| <b>Total Western Australia</b>  | <b>75</b> | <b>60</b> | <b>132</b> | <b>6.9</b>                 | <b>5.2</b> | <b>6.1</b> | <b>1,290</b>                     | <b>616</b> | <b>1,901</b> |
| <b>Tasmania</b>   |           |           |            |                            |            |            |                                  |            |              |
| 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           |
| <b>Total Tasmania</b>   | <b>28</b> | <b>22</b> | <b>51</b>  | <b>10.2</b>                | <b>6.7</b> | <b>8.4</b> | <b>407</b>                       | <b>235</b> | <b>636</b>   |
| <b>Northern Territory</b>   |           |           |            |                            |            |            |                                  |            |              |
| 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            |
| <b>Total Northern Territory</b>   | <b>3</b>  | <b>2</b>  | <b>2</b>   | <b>0.8</b>                 | <b>1.8</b> | <b>1.3</b> | <b>66</b>                        | <b>89</b>  | <b>150</b>   |
| <b>Australian Capital Territory</b>   |           |           |            |                            |            |            |                                  |            |              |
| 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           |
| <b>Total Australian Capital Territory</b>   | <b>8</b>  | <b>15</b> | <b>24</b>  | <b>6.0</b>                 | <b>8.9</b> | <b>7.2</b> | <b>81</b>                        | <b>342</b> | <b>421</b>   |

(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 8: One, five and 10-year relative survival by cancer site, diagnoses in 1998–2004**

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

|   |      |      |      |      |     |     |     |     |     |
|---|------|------|------|------|-----|-----|-----|-----|-----|
| 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 9: 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   |                  |
|---|-------------|------------------|-------------|------------------|-------------|------------------|-------------|------------------|
|   | per         | 95 per cent      | per         | 95 per cent      | per         | 95 per cent      | per         | 95 per cent      |
| <b>Males</b>  |             |                  |             |                  |             |                  |             |                  |
| All cancers<br>(C00–C96 <sup>(a)</sup> , D45–D47 <sup>(b)</sup> ) | 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        |
| <b>Brain (C71)</b>  | <b>20.8</b> | <b>19.3–22.4</b> | <b>19.7</b> | <b>18.3–21.2</b> | <b>18.7</b> | <b>17.5–19.9</b> | <b>18.5</b> | <b>17.5–19.6</b> |
| 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<br>(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<br>(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        |
| <b>Females</b>  |             |                  |             |                  |             |                  |             |                  |
| All cancers<br>(C00–C96 <sup>(a)</sup> , D45–D47 <sup>(b)</sup> ) | 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        |
| <b>Brain (C71)</b>  | <b>19.9</b> | <b>18.2–21.6</b> | <b>20.4</b> | <b>18.8–22.0</b> | <b>18.3</b> | <b>17.0–19.7</b> | <b>19.4</b> | <b>18.1–20.6</b> |
| 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<br>(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<br>(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 9 (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   |                  |
|---|-------------|------------------|-------------|------------------|-------------|------------------|-------------|------------------|
|   | per         | 95 per cent      | per         | 95 per cent      | per         | 95 per cent      | per         | 95 per cent      |
| Persons                                   |             |                  |             |                  |             |                  |             |                  |
| 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        |
| <b>Brain (C71)</b>                        | <b>20.4</b> | <b>19.3–21.6</b> | <b>20.0</b> | <b>19.0–21.1</b> | <b>18.6</b> | <b>17.7–19.5</b> | <b>18.9</b> | <b>18.1–19.7</b> |
| 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 10: 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   |
| Males                                     |             |                  |             |                  |             |                  |             |                  |
| 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)                               | <b>20.8</b> | <b>19.3–22.4</b> | <b>19.7</b> | <b>18.3–21.2</b> | <b>18.7</b> | <b>17.5–19.9</b> | <b>18.5</b> | <b>17.5–19.6</b> |
| 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        |
| Females                                   |             |                  |             |                  |             |                  |             |                  |
| 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          |



**Table 10 (continued): 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 |
| <b>All cancers (C00–C96(a), D45–D47(b))</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      |
| <b>Stomach (C16)</b>                             | 16.9      | 16.1–17.8      | 18.9      | 18.1–19.8      | 21.2      | 20.3–22.0      | 24.7      | 23.9–25.6      |
| <b>Colon (C18)</b>                               | 48.9      | 48.2–49.6      | 53.0      | 52.3–53.7      | 56.7      | 56.2–57.3      | 61.3      | 60.7–61.8      |
| <b>Rectum (C19–C20)</b>                          | 48.4      | 47.3–49.4      | 51.7      | 50.7–52.6      | 57.7      | 56.9–58.5      | 62.9      | 62.2–63.6      |
| <b>Colorectal (C18–C20)</b>                      | 48.7      | 48.1–49.3      | 52.6      | 52.0–53.1      | 57.1      | 56.6–57.5      | 61.8      | 61.4–62.3      |
| <b>Pancreas (C25)</b>                            | 2.8       | 2.4–3.2        | 3.5       | 3.1–3.9        | 3.8       | 3.5–4.2        | 4.6       | 4.2–5.0        |
| <b>Lung (C33–C34)</b>                            | 8.5       | 8.2–8.8        | 9.5       | 9.2–9.8        | 10.6      | 10.3–10.9      | 11.8      | 11.5–12.1      |
| <b>Melanoma of skin (C43)</b>                    | 86.5      | 85.8–87.1      | 89.4      | 88.9–89.9      | 91.4      | 91.0–91.8      | 91.6      | 91.3–92.0      |
| <b>Kidney (C64)</b>                              | 46.5      | 44.9–48.2      | 50.8      | 49.4–52.3      | 58.6      | 57.5–59.8      | 65.8      | 64.8–66.7      |
| <b>Bladder (C67)</b>                             | 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      |
| <b>Thyroid (C73)</b>                             | 83.6      | 81.7–85.4      | 86.8      | 85.2–88.3      | 92.1      | 91.1–93.0      | 93.4      | 92.7–94.1      |
| <b>Hodgkin lymphoma (C81)</b>                    | 71.7      | 69.3–74.0      | 77.1      | 74.9–79.2      | 82.5      | 80.7–84.2      | 85.2      | 83.7–86.6      |
| <b>Non-Hodgkin lymphoma (C82–C85, C96)</b>       | 46.9      | 45.7–48.1      | 50.1      | 49.1–51.2      | 53.1      | 52.2–53.9      | 62.1      | 61.3–62.8      |
| <b>Leukaemia (C91–C95)</b>                       | 37.6      | 36.4–38.8      | 42.7      | 41.6–43.8      | 42.9      | 42.0–43.9      | 47.8      | 47.0–48.7      |
| <b>Unknown primary site (C26, C39, C76, C80)</b> | 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 11: 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 |                |
|--|-----------|----------------|-----------|----------------|-----------|----------------|-----------|----------------|
|  | p         | 95 per cent CI | p         | 95 per cent CI | p         | 95 per cent CI | p         | 95 per cent CI |
| Persons aged 0–14 years                              |           |                |           |                |           |                |           |                |
| <b>All cancers (C00–C96(a), D45–D47(b))</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      |
| <b>Bone and connective tissue (C40–C41, C47–C49)</b> |           |                |           |                |           |                |           |                |
| 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      |
| <b>Brain and central nervous system (C70–C72)</b>    |           |                |           |                |           |                |           |                |
| 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      |
| <b>Leukaemia (C91–C95)</b>                           |           |                |           |                |           |                |           |                |
| 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](http://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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