



**SURVEY ABOUT BRAIN TUMOUR CARE COORDINATORS UNDERTAKEN BY  
BRAIN TUMOUR ALLIANCE AUSTRALIA INC IN JANUARY 2011 –  
PRELIMINARY REPORT AND DISCUSSION.**

Introduction

More than 1,400 people in Australia are diagnosed with a primary malignant brain tumour each year and more than 1,000 people die from these tumours each year.

There was no significant change in five-year survival for brain tumour patients between 1982-86 (20%) and 1998-2004 (19%) – latest available statistics.

Although ranked only 19th in terms of incidence, brain tumours rank 4th in terms of person years of life (PYLL) lost to age 75.

This paper summarises the results of a survey on the need for brain tumour care coordinators undertaken by Brain Tumour Alliance Australia (BTAA) – with a view to providing supporting evidence for the funding of additional coordinators.

**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 twelve 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.

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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 of 18% from the BTAA email invitation (83/455) is considered by the organisers to be a good response rate compared with other recent surveys involving the same database and its international constituents (e.g. Mo Mowlam survey). 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'l	1	2	3	2	1	0	1	0	0	10
Neurosurgeon	2	1	2	2	3	0	0	0	0	10
Patient/survivor	4	4	5	2	3	0	4	0	0	22
Nurse	7	7	9	2	3	1	1	1	0	31
Medical oncologist	1	2	1	0	2	0	1	0	0	7
Other health worker	0	1	1	0	0	0	0	0	0	2
Radiation oncologist	1	0	0	0	0	0	0	0	1	2
Interested member of the public	1	0	1	0	0	0	0	0	0	2
<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>

The relative number of neurosurgeons who responded was a surprise and the small number of radiation oncology participants a disappointment.

Respondents such as social workers have been subsumed in “allied health professional”. In any future survey it might be useful to deliberately seek out hospital social workers, together with general practitioners who may have had contact with a brain tumour patient, and also palliative care workers, although the latter group are not usually involved when the patient is undergoing active treatment.

It should also be noted that we did not ask the former caregivers how far in the past their personal experience was but there are unlikely to be many whose experience was greater than about five years because the former caregivers in the BTAA database are of more recent experience.

From previous involvement with on-line surveys, including a major international one (the Mo Mowlam survey) which included the question of how much should a brain tumour patient reveal publicly of their diagnosis, it is clear that potential respondents are generally not prepared to spend a great deal of time on an electronic survey. In regard to this survey, of the group of 455 email recipients who received a personal invitation, 224 did visit the survey of which 131 completed it. Whether the other 93 visitors were put off by the length is unknown. There were no partial completions, in other words, when respondents commenced the survey they worked their way through to the final “submit” button.

## Categories and questions

It may have been a mistake to offer a separate category for “family member” respondents because in studying the answers it appears that several “family members” were also providing caregiver support and may have interpreted that category to be reserved solely for *full-time* caregivers. In the further analysis which is to follow, the answers from respondents in these two categories have therefore been combined.

In order to avoid giving the survey the appearance of great length one question in the survey was reserved exclusively for patients/survivors and caregivers (answered by 71 respondents) and two questions for professionals and health care workers (answered by 67 and 60 respondents). No questions were compulsory but all respondents allocated themselves to a category in the first question and 122/131 respondents provided contact information in the final question, which enabled the correlation to be made in the table above which associates a person’s category with their State/Territory.\* Furthermore, this information protected against multiple responses from one individual.

In retrospect the sub-questions in these category-specific questions should have been presented as separate questions, to enable ease of comprehension, answering, and analysis. A number of respondents chose to combine the sub-questions and provide a single comprehensive answer.

## Question 2

53 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; Royal Melbourne Hospital.

**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.

Twelve 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 care coordinator positions. For example, the McGrath Foundation has funded at least 55 breast care nurses who have supported 4,500 newly diagnosed families\* and they are not the only breast care nurses in Australia.

The NSW Cancer Institute funds 58 cancer nurse coordinators (CNCs) across NSW\*. It is not known how many of these CNCs interact with brain tumour patients but see later for the answers to Question 4 of this survey about patient interaction with an allocated staff member.

The distinguishing feature about brain tumours, in regard to the provision of care coordination, is that they 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, and neurology, to name a few.

Patients and families need to steer an extremely complex and intense pathway through the medical minefield and even the toughest of patients soon become overwhelmed and confused. This is identified in several of the responses from patients and caregivers quoted below.

Health care workers therefore need specific knowledge of the unique problems their brain tumour patients might encounter. It is not known how many of the 58 NSW CNCs mentioned above have that knowledge and experience but their generalist skills could be relevant to at least some aspects of the brain tumour patients' problems.

Several of the responses to this question revealed that some treatment centres are also providing care for brain tumour patients in a part-time or incidental way, particularly in regional settings or smaller centres where the numbers of brain tumour patients were not high. See these responses:

“(we have a) nurse attached to our unit who contacts the brain tumour patients monthly and partially fulfils this role”;

“My title is Cancer Care Coordinator but I don't only cover brain tumour patients. I also coordinate the care for head and neck cancer patients and patients with melanoma”;

“I work in the regional setting and only care for a very small number of patients diagnosed with primary brain tumours. My role is usually limited to providing information and support to patients and their carers returning to the regional area following treatment or in the palliative setting”;

“By default I am a coordinator ie I provide regular follow up to XXXX Neurosurgery community brain tumour patients. By providing follow up I become (the) brain tumour patients' contact person & trouble shooter”;

“I am the brain tumour support nurse on the neurosurgery ward at XXXXX. It is not a funded position so it is done as part of my clinical nurse position”;

“I am not a brain tumour CC per se but I am involved in coordinating care for patients undergoing chemo radiation therapy and as such I am involved with brain tumour patients”;

### Question 3

More than 80 respondents expressed an opinion on what title should be given to the position. Four suggestions were made in the body of the question: brain tumour cancer care coordinator; brain tumour care coordinator; system navigator; brain tumour patient assistant. “System navigator” is a term used occasionally in the USA.

The preferences were:

Category/Title	Brain tumour cancer care coordinator	Brain tumour care coordinator	System navigator	Brain tumour patient assistant	Other
Family member; caregiver/former caregiver	1	11		2	5
Allied health professional	2	3			3
Neurosurgeon		8			
Patient/survivor	2	7		1	1
Nurse	4	6			13
Medical oncologist	2	3			2
Other health worker					2
Radiation oncologist		2			
Interested member of the public		2			
<b>Total</b>	11	42	0	3	26 (82)

There was clear support from within all groups, particularly by patient/survivors and family members and caregivers/former caregivers, and the neurosurgeons, for the description “brain tumour care coordinator” but more than half the nurse respondents offered alternative titles, mostly unique. No respondent supported “system navigator”.

One specialist made the point in supporting the description “brain tumour care coordinator” that it “encompasses both malignant and benign disease”. A patient/survivor wrote, while supporting the same description, “I think the word ‘cancer’ needs to be left out to enable those with ‘benign’ tumours to still feel as though they too can access help”. However, a nurse respondent suggested either “neurology cancer care coordinator” or “Brain and Spinal Cancer Care Coordinator” and wrote: “It should definitely not be restricted to ‘brain tumour’ only”. Another interesting comment was “Something that involves the patient, not the cancer being cared for.” Then again: “brain tumour cancer care coordinator, as the name cancer care coordinator is known and accepted”.

The title is important because it must be something that patients/survivors and their caregivers are comfortable with and it helps to identify if the position is grounded within only one arm of the standard treatment path for primary malignant brain tumours or can be accessed by patients whether they are receiving neurosurgery, radiation therapy or chemotherapy.

From a patient advocate perspective a coordinator who is accessible at all treatment stages is preferable, particularly with the possibility of second and more craniotomies and the developing treatment options regarding reirradiation\* or later stereotactic radio surgery, even having regard to the emergence of the combined chemo-radiotherapy as part of standard care for glioblastoma brain tumours.

Some of the “other” descriptions listed by respondents (in the order their answers were received) included:

Brain tumour patient's needs coordinator.  
 Brain Multidisciplinary Meeting Co-Ordinator  
 Neuro-oncology Nurse  
 Palliative Care nurse  
 Brain Tumour Cancer Nurse Coordinator  
 Care coordinator for those diagnosed with Brain Tumour  
 Brain Tumour Support Clinical Nurse  
 Brain tumour patient assistant  
 Brain Tumour Nurse Coordinator  
 Brain tumour Support Coordinator or Brain tumour support officer  
 Neuroscience Nurse Consultant and brain tumour support group co-ordinator  
 Brain tumour CCC  
 NeuroOncology Nurse Coordinator  
 Brain Tumour Support Officer Cancer Services  
 Brain tumour/cancer care coordinator  
 Neuro-oncology cancer care co-ordinator  
 Specialist palliative care nurse  
 Clinical Nurse co-ordinator- neuro- oncology.  
 Neurology Cancer Nurse Coordinator

While some may consider this question of title to be minor and incidental, several of the suggested alternate titles warrant comment because of the thinking that may have prompted them:

(1) From a patient advocate perspective the occupant’s role should be more than being the coordinator of a Multi Disciplinary Team (MDT) meeting, or support group co-ordinator, although these two roles could be included within it;

(2) While it is acknowledged that many patients will eventually receive palliative care, will they or their family and/or caregivers be comfortable with a connection to a coordinator with that title early in their journey? and

(3) The inclusion of “oncology” in the proposed titles may convey the impression that the position is confined to that area of treatment i.e. medical oncology, with the slight possibility of the occupant being accessible during radiation oncology. Information contained in the responses to later questions will help to identify what patients/survivors and family members/caregivers believe they have missed out on, and what they seek.

#### Question 4 – What the patients and their caregivers desire

Question 4 was a five-part question directed to patients/survivors and caregivers/former caregivers and designed to identify if they had had access to a specific individual to assist them in navigating their journey.

21 patients/survivors and 41 caregivers/former caregivers/family members responded to the first sub-question, which represented an overwhelming majority of all survey respondents from these categories. As mentioned above, many respondents gave a combined answer to the five sub-questions but most differentiated sufficiently between the first sub-question about contact with a specific staff member and the last sub-question asking if they would welcome access to assistance from a specific person.

The responses from the two categories to the first sub-question asking if they had had access to a specific individual are tabulated below.

#### *Patients/survivors*

Category/State	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Unk	Total
No contact	4	3	4	1	1	0	4	0		17
Contact	1	0	0	1	2	0	0	0		4 (21)

#### *Caregivers/former caregivers/family members*

Category/State	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Unk	Total
No contact	3	4	5	2	5	2	4	0	0	25
Contact	3	3	1	2	1	0	0	0	1	11
Unclear	1	1	1	2	0	0	0	0	0	5 (41)

Clearly there had been only minimal contact on the part of patients and not much better on the part of caregivers etc.

23 patients/survivors and 46 caregivers/former caregivers/family members responded to the fifth sub-question, asking if they would welcome such assistance. Their responses are as follows.

#### *Patients/survivors*

Category/State	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Unk	Total
Welcome	4	4	3	3	1	0	4	0	0	19
Not welcome	0	0	1	0	0	0	0	0	0	1
Unclear	1	1	1	0	0	0	0	0	0	3 (23)

#### *Caregivers/former caregivers/family members*

Category/State	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Unk	Total
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Welcome	6	5	6	2	4	0	5	0	1	29
Not welcome	0	0	1	0	0	0	0	0	0	1
Unclear	5	2	1	3	4	1	0	0	0	16 (46)

Again, the positive response by both patients/survivors and caregivers/former caregivers/family members is overwhelming.

However, it is within the commentaries provided by respondents to the entirety of Question 4 where a feel for their experiences is obtained. Some of those commentaries, in the order they were received, are as follows.

### *Patients/survivors*

[Note: The extracts that follow from patients, carers and health professionals have not been altered, except for the correction of typographical mistakes and misspellings. Words excluded are identified by “...”. The quotations therefore represent only one perspective of an interaction between two people, or two groups of people. Nevertheless they are useful as examples of *how the particular responder saw the situation*, whether they be a health professional, patient, or carer.]

“1) Yes, XXXXXXXX, I had her (the care coordinator) from mid June to end of July 2010 .... I ... have navigated this journey alone ever since. I had email contact and used it often in that month, she was swift to advise me what to do with the phenytoin rash I developed, when I thought it was an antibiotic rash (as did the GP and XXXXX ER doctors). Available for all aspects of my treatment. Contacted other specialists (doctors, dieticians) for clarification for me on treatment options - very useful at the time. ...I sent probably about 8 emails in that month - long ones, full of questions and in the end she said that she had too much of a patient workload to keep answering them, soon after she was off work. I really miss having that avenue for questions now. 4) Yes she did, at the time though I was hell bent on alternative treatment options and she was very suppressing on that...in the end, I settled down. I did find the party line of "Alternate treatment bad!" irritating though, but in the early days of getting a GBM diagnosis all you want is to get treatment options right...unfortunately there is no definitive treatment option...as I am now aware. 5) Yes, I would, I miss not having a knowledgeable nurse available to direct my queries to the Doctors and other professionals, in that month I had her, I felt like I had a steady point in all the chaos.”

“As I went through the public health system, the wait and information was sometimes slow to access. After discovering I had a tumour, my doctor contacted the hospital, and a meeting was arranged to speak with a surgeon the next day. I was told the surgery would be quite soon. However, the wait, and lack of info did become quite frustrating. I was told to contact the hospital with any questions, or if any symptoms appeared. The surgeon who first spoke to me, did not do my surgery, nor did the next one who called to say he would be doing the surgery. For reasons I don't know, I was passed on to another surgeon - I have not yet met my surgeon - often a different doctor (and they each may give me a different answer to my questions), when I go for regular scans/meetings. While in hospital following surgery, it was difficult to remember what the doctors told me when visiting patients on the ward - memory problems do seem to go with brain surgery. It would have been best to have the answers written down, or have a family member with me to recall info given.”

“No advice or assistance was provided or offered. It was left to my wife and son. I would absolutely welcome any assistance that would enable family members to have knowledge of what potentially might happen following surgery and to have a support group available afterwards.

“1) no, but having a specialist person to educate me would have been extremely useful 2)no 3) no 4) no 5) of course, the overwhelming time after diagnosis is a maze which we stumbled through with no 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”

“1. No but I wish that I did have. I found the whole system very confusing and overwhelming. Especially dealing with the multitude of tests, medication, specialists, epilepsy, OT, physio. I would love to have someone help me through this maze.”

“I had access to neuro surgery team nurse who was very helpful but was only able to contact her during office hours”

#### ***Caregivers/former caregivers/family members***

“We were not advised about any one person who could be a contact for every aspect of our daughter’s treatment; only various specialists who were only available during normal office hours and who usually were slow to respond/reply. 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. I am not aware of anyone who is employed specifically to assist brain tumour patients.”

“(1) my daughter was appointed an oncologist from the children’s hospital who manages her care/treatment. (2) yes - The oncology clinic provides an after hours contact number for any emergencies. You could always speak to a specialist or can come in at short notice for medical assistance. (3) no (4) mostly sufficient however the oncologist is always time poor - extremely overwhelmed by many patients and is away quite often overseas. Our last 3 visits he has not been available and have been seen by oncology fellows. (5) yes – absolutely”

“A social worker, working in the general cancer area could be contacted within hospital hours only. She had no expertise in assisting brain tumour patients. She was directed by our daughter's Oncologist to "counsel/assist" in dealing with the "reality" of the prognosis of a GBM 4. (ie death within months). I could not say that the journey was made easier by her information or by any of the then available written material given to us. However, the social worker was helpful in assisting to navigate the health system which was made unnecessarily stressful by administrative staff. Access to a person of specialist knowledge available after hours who could be a "mediator" between patient/caregiver and the medical profession in all aspects of treatment, thus assisting in coordinating the care and reducing the stress for all who find themselves thrust into the brain tumour journey.”

“No such service was available at any stage of my husband's 10 and a half year battle. I would really have benefited from such a service during the last two months when isolated from our NO and dealing with non cancer medicos.”

“(1) No, told to contact emergency department of treating hospital. Our local GP was available (surgery hours) and he, unfortunately, had significant experience with GBM and treatment. (2) Not really. (3) N/A (4) Our local GP was great- understanding and compassionate and explained aspects that needed clarification. (5) This would be most helpful and make the journey much easier.”

“We did not have much assistance at all!! It was a total shambles!! Yes you need a person as mentioned above very badly.”

“I did not have access to this assistance and would have found it most helpful if I had. It was a difficult enough journey without the stress of coordinating the various areas involved - eg neuro surgeon/GP/Oncologist/blood test/MRI/Radiation/Medications etc etc. A bit bewildering not knowing what a Registrar/Dr etc role was and having to make decisions as to who to see and when as well as where. I left full time employment to take on the role as carer but still found it challenging”

“There was no offer of support. I would strongly support the introduction of this role, supporting patients with brain cancer to access not only hospital services, but others as well including counselling services, Centrelink, support groups etc”

“No we have had no assistance in this. It would be good to have someone to talk to who is experienced in this area. Before the diagnosis, we had no knowledge of Glioblastoma Grade IV and it is just devastating. The internet is useful but it is so negative, it would be good to speak to someone local.”

“Yes, the main problem we face is that we feel my mum (the brain tumour patient) has no one overseeing her treatment. There are doctors for each aspect of treatment, but who is looking at the big overall picture?”

“5. We weren't offered or directed to, or knew of such support available on the XXXXXXXX. 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, a difficult journey in such a complicated area. Specialists just seem to think that their role is to operate, collect their money, and see you later.”

“No not really. Would have welcomed someone to talk to 'after hours' if possible. We were lucky my family is Medical (Nurses and Physios) so that was a big help.”

“We had an oncology liaison nurse who was contactable during normal hrs. There was no out of hours liaison nurse. She did not always have information for you but would find out or you. She always supported our decisions. I think it would be good for a 24hr service.”

“1. no, we went to a brain tumour support day 2. 3. no 4. na 5. yes it would have been helpful early on. We had been dealing with it for 5 years before this (support) day was even offered.”

“1. no, I was never given access to this level of support at the hospital or nursing home. At the XXXX Hospital, or XXXXXXXXXX nursing home. 2. na 3. na 4. na 5. yes and I insist that this service and assistance be included in low and high care nursing homes particularly, and always in the language of the patient. N/A = Not applicable”

“Yes we had a contact person but only in business hrs. Not appropriate to share (the care coordinator) with others who were not neuro-oncology. Knowledge reasonable not always accessible and yes made the journey easier. A care co-ordinator is absolutely essential.”

In Appendix B we have reproduced more than 70 responses to a question about access to care coordinators which was part of an international survey by the International Brain Tumour Alliance in late 2010. Most of those respondents did not have access to a care coordinator but some did have direct access to other health personnel.

#### Question 5 – The view from the other side

The responses to Question 4 clearly indicate that there is a desire by patients/survivors and their caregivers that they have access to a specified care coordinator who might be able to assist them as they travel the brain tumour journey. What then is the capacity and interest of those who work in the treatment centres to create such a position and how would it be organised?

60 people responded to Question 5 and, as with the answers to the previous question, these respondents also tended to provide a combined response. Comments were received from all the neurosurgeon participants in the survey, together with the vast majority of other respondents from the health services. The individuals’ responses (some of which are reproduced below in order of receipt by category) convey a very useful snapshot of what has been tried and what might be feasible in the various centres where brain tumour patients are being treated.

#### *Neurosurgeons*

“We have sought to create a position. Funding is difficult and also finding a suitable person. It is an absolute necessity to running an effective multidisciplinary brain tumour clinic and providing good care. A nurse would be fine but they must have a special interest and be empathic by nature. An occupational therapist would be another option as many patients are working and we need them monitored to make sure they are safe at work and driving. Social worker would also be an option.”

“1. Yes 2. At the XXXXX we did have a cancer coordinator but the job seems to have disappeared. 3. In XXXXX yes for adults but in children there would need to be a combination with another role. 4. a caring committed person. Not necessarily a nurse, could be a social worker or other health professional. .... A belief in traditional western medicine.”

“1. Yes 2. Yes 3. F/T with more than enough work. My practice could support 2 F/T positions 4. No 5. Experience in the health industry would be preferable but anyone with compassion and organisation skills would be welcomed”.

“I would absolutely welcome such a coordinator. I think patients with brain tumour face unique difficulties and have very little support currently in the community. This would be a full time occupation in the area I practice in. We have applied both to the local hospital and to the cancer council to create such a position. This was rejected on the basis of inadequate funding. I think a nurse, RN with at least 5 years experience with at least some neurosurgery experience would be best suited to the role. I see the role as mostly coordinating referral to the appropriate specialist service, but experienced nurses would be able to answer some basic questions and gain patient trust and confidence.”

### ***Medical oncologists***

“1 We have 1- but since starting 18 months ago she has gone from working 20 to 50 hours per week. 2 We have created the position as our unit could no longer survive without one. 3 Our coordinator is trained in general oncology - and assists as necessary in the clinic and ward - she also tries to train others in the clinic 4 I would push for senior nursing - there are so many needs but if we don't get the medical part right the other becomes irrelevant -however the role of our care coordinator spans nursing social work counsellor- data manager - even rent negotiator-once the medical part is done it would allow us to build up a dedicated team of allied health-palliative care rehab etc as well. 5 my patients need the basics - how do I take my tablets -what is my count - I have a fever or headache what do I do? They lose their scripts - call in from XXXXX when they are having seizures - some carers just call weekly to be reassured they are doing their best and to have someone they trust listen to all the worries they have”.

“1. Definitely yes 2. yes - but only a part time position and no dedicated ongoing funding 3 yes, definitely enough work just in brain tumour patients 4. I believe position best filled by an experienced nurse, with support from other members of the team as required”.

### ***Radiation oncologists***

“1 and 2. We have one. 3. We see 40 new GBM cases/year and 10 low grade gliomas. Brain metastases patients are not within the current remit. This workload already constitutes a full-time role. 4 and 5. currently CNC 2 but there are non nursing CC's eg social work, allied health, physios in other tumour site. It should be someone with clinical insight and with experience.”

### ***Allied health professionals***

“In oncology yes but we have a special neurosurgical ward where all the nursing staff could be described as brain tumour care co-ordinators 2.no 3.yes 4.yes”.

“I think this role would be invaluable. I currently am a care coordinator for brain tumours and other types of cancer (head and neck, melanoma) and I really don't think I am doing an adequate job for the brain tumour patients due to time and resource restrictions. For example, information provision and education is given in a very ad hoc way but I have not had time to try and

streamline the processes and look at service development initiatives. I think there is huge scope for a care coordinator to be solely dedicated to brain tumour patients. I do not think they need to be a nurse. I think they could be a nurse or allied health professional. I think a main role of a care coordinator is to work as part of a multi disciplinary team, ensuring all members are involved as appropriate and ensuring that good communication occurs between the team members. It should not matter what professional background the care coordinator is from. I think the position should be a combination of clinical and service development/improvement, thus the person appointed should have these higher level skills and abilities.”

“1. yes 2. yes 3. yes 4. No, I feel that nurses would do a great job. However, it could be possible to train others in this role. 5. I feel that a specific course could be created to appropriately train the individual to this role. This course would involve appropriate social working skills, organisational skills and medical knowledge in relation to brain tumours.”

“40 1,2) There is one position of a Cancer Nurse Coordinator - Neurology working in XXXXXXXX. However this is a very large and complex role and would benefit from additional staffing to meet the needs of this patient group. 3)There are other CNCs for other specialty cancer groups eg gynaecology, haematology, head and neck, thoracic, urology, upper GI, Paediatrics/Adolescent, and Rural Liaison. 4)A Nurse is very appropriate if there is only one position, as the patients benefit from the support for medication management and understanding complex medical procedures. However, if a service has more than one staff, the second position would be appropriate for an Allied Health position to enhance the role to support case management and function.”

“(1) XXXXXX established a pilot brain tumour support position in July 2008. This position was initially set up at 0.4 eft and funded via a philanthropic grant from the XXXXX Memorial Fund. Whilst XXXXX is supportive of the role, the Brain Tumour Support Officer position continues to be funded via grant and bequest, rather than as an ongoing position through the health service and has recently increased to 0.5eft. (3)I think that there is sufficient work within this role so that the worker iss solely focussed on this position. I think to support another tumour stream would be difficult in an already very demanding role. Combined with a "non clinical " role might be best. (4) THIS POSITION DOES NOT NEED TO BE OCCUPIED BY A NURSE. (5) Someone in this role should be experienced in working with people with neurological impairments, cognitive, behavioural and physical, are skilled at identifying supportive issues and needs of patients and families. This position requires a wide range of interpersonal skills and experience, at XXXXX this position is a Grade 3 Senior Clinician (Allied health).Professional categories suitable would be Occupational therapist, Speech therapist, Social worker, Nurse, maybe psychologist & physiotherapist”

“1. Working in the radiation department - there may not be enough numbers of patients - but a surgical CC linking with the treatment centre would be beneficial 2. No 3. Not enough work - my role covers most cancers patients having chemorad for solid tumours 4. I think nurses are best suited to the CC role due to their knowledge of physiology, treatments, side effects etc. No 4 post grad qualification 5.”

“1. We already have a neuro-oncology cancer care coordinator at the XXXX 2. ditto 3.The position occupies most of the cancer care coordinators time but they are also responsible for

colorectal oncology patients. 4. No, this position at XXXX is occupied by an allied health person. 5. The occupant needs to have some understanding of the hospital system and patients journey. They need to have empathy with the patient and their family and to be able to clearly guide them through the journey. The CCC becomes the single contact person within the system for the patient and family. They need to problem solve and understand the mechanisms of the MDT and who to refer to for the different circumstances.”

### ***Other health workers***

“1. Yes 2. We have one 0.8EFT 3. absolutely enough work for a CNS/brain coordinator 4. Traditionally is a nurse, ZJ7 is the classification. we ask for paediatric nurse qualifications and chemo accreditation and at least 5 yrs paed experience and preferably caring for children with brain tumours. 4 and 5) this depends on the role. if navigating only- then could be anyone, if giving information, educating families and assisting the medical staff in writing referrals etc and linking with regional centres and completing documentation for XXXXXX and referrals to XXXX - should be a nurse. If preparing roadmaps, should ideally be a nurse. Our CNC is funded by philanthropy.”

### ***Nurses***

“My work setting has not attempted to establish a position, but there would be sufficient load in the organisation as whole to establish such a position. I believe the position needs to be filled by an experienced nurse, with expertise in brain tumour. Coordination of patient care requires an holistic understanding of all needs - it is more than case management. To appropriately negotiate access to appropriate services, CCCs need to understand clinical and supportive care needs.”

“1 XXXXXXXX formulated a proposal in 2007 to support the addition of a Brain Tumour Coordinator to the neurosurgical practice. 2. The Position commenced in May 2007. 3. From May 2007 to April 2010 the brain Tumour coordinator has seen 376 brain tumour patients. 4. Yes this role should be occupied by an advanced practice nurse who has specialist qualifications in neuroscience nursing. An advanced practice nurse role is based on holistic practice they also have the knowledge that is essential to educate patients and families and the ability to identify patients needs and direct patients to other allied health staff such as social workers when appropriate.”

“I feel the role would greatly improve the quality of care provided to brain tumour patients and their families. In my opinion an experienced nurse with neurosurgical & oncology experience would be ideal. Based on the cancer care coordinator model they would require post graduate nursing qualifications and clinical expertise. In an ideal world a specific course could be developed at a tertiary level for the role as has been done with the specialist Breast Care Nurse course provided by a University (La Trobe or Monash?) in Melbourne. This would provide a means to form a professional group and maintain guidelines for practice.”

“I believe there is a great need for someone in this role as patients/carers/relatives so easily become lost in the system and so much improvement in so many ways could be achieved at a time when the whole world is falling apart.”

“We have created a position, unfortunately this position should cover a health region -i.e "an ICS" catchment area, due to the limited number of patients any one hospital may service, better to not "re invent the wheel" in every hospital! The role should be for brain tumour patients only as their needs are VERY different to other cancer patients' needs - they should be a senior nurse with background of "grief and loss" who has knowledge of community supports but is employed by the acute hospital system, so they have access to specialised professionals, i.e. neuro-psych. social workers, neuro-occupational therapist and physiotherapist.”

“We would not have the volume of patients to warrant a dedicated position of a Brain Tumour cancer care coordinator. I think this position should be occupied by a nurse grade 7 with at least 5 years clinical experience and if does not have is planning to obtain Masters of Nursing. Nurses have a good understanding of the entire care trajectory. They have a knowledge of the pathophysiology, ability to provide comprehensive assessment, understand treatment modalities, side effects of cancer and treatment, possess effective communication skills, and therefore are well placed to offer appropriate assessment, care, information and support to this cohort of patients and their carers.”

“Our neurosurgery ward would definitely benefit from this type of position being funded. Myself and my NUM have talked about writing a proposal for such a position to be funded for our area. I started doing a brain tumour database in July last year to keep track of how many tumour patients we had through and also the different diagnosis. It would be great to have more time to spend with patients and their families both before and after surgery and also the time to gain more knowledge about the less common tumours and their treatments. I think the position would be of more benefit for a nurse as they also have the background anatomy and physiology knowledge but don't think it needs to be limited to nurses”

“I would welcome the capacity to create and fill a position of a dedicated brain tumour cancer care coordinator. This is a position that should be occupied by nursing professionals since it has a lot to do with educational and patient support. The medical knowledge is an essential element in this role in order to deliver better support. This role is not to replace social worker or other professionals; on the contrary it is to complete the whole picture. I have made an effort in past two years try to develop the brain tumour support service at XXXX with XXXXX's help, we now have temporary private funding 4 days per fortnight to deliver brain tumour support.”

“My work is already in this role, however I am employed only 1 day per week and this has not been permitted for increase to date. The complexity of brain tumour patients and the support networks does require significant time so I do believe there is scope for a co-ordinator to be doing 3 days per week at my current place of employment. This would allow time for direct patient care together with professional development and time to provide service in education for colleagues. I believe a nurse is the correct person for this position as it allows for good understanding of pathophysiology, gold standard treatments, side effects of treatment, being able to triage unwell patients if they contact the hospital, etc.”

“I would welcome the creation of such a position as my role overlaps to include this role, and i have expanded my role as it has developed over the past 8 years. 3) Other cancers that could be included would be spinal tumours.4) Yes a nurse consultancy level 5) nurse only recommended.”

“Patient numbers for dedicated brain tumour coordinator would be too small, however, combined with Head& Neck, unknown primary or Met. Melanoma would be feasible. Oncology Nurses educated and experienced at CNC level would be appropriate requirement.”

“1 -> yes - the brain tumour role that I undertake is too much to incorporate into my dedicated role 2 -> not yet ; lots of talk about it but uncertainty where to direct the request to create the position 3 -> YES there is sufficient work for brain tumour position - it would be difficult to merge it with another cancer specialty because of the specialist knowledge required 4 & 5 -> I am a nurse & fulfill the role -> a SW would have difficulty with the clinical aspect of the role. For a nurse, it needs to be a Level 3 position because specialist knowledge, clinical & community skills are required for the role -> how I do the role is by coordinating care, linking patients to appropriate community services; liaising with community services ; trouble shooting ; counselling ; making sure treatment happens ; monitoring patient response to treatment ; family support including ensuring children in the family are considered ; & so on.”

“We have had discussions just yesterday regarding the need for support of Brain Tumour patients. We would incorporate the role into the model we use for Lung and Colorectal cancers, which is for a Level 3 Nurse position. The person would also need to have another tumour stream to look after as we don't have the numbers of patients. My thoughts are that Brain should go together with Melanoma, and/or Head and Neck tumour streams.”

“Mostly likely not as we are both a hospice and community outreach service. The brain tumour coordinator would better sit in a public sector hospital where brain tumours are diagnosed. We did seek to create this position with the XXXXXXXXXX and XXXXXXXXXX. However funding the position was an issue for both organisations. If the coordinator sat within a neurological division, they would be able to assist with other brain related issues A nurse would be the best person as they tend to have a better idea re: resources available, symptom management and where counselling support is available. The key is that the individual needs to be passionate about working with these clients and their families. Ideally, the individual should have a strong background in palliative care as the majority of people will require palliative care at some point in time.”

“ 1.Already have 1.3 FTE level 4 SRNs in post 2. There is plenty of work. In XXXXXX last year alone there were 186 new patients, in addition to the increasing longevity enabled by new chemotherapeutics advancements. There are a mean of 175 patient episodes of care per month. 4. This position requires a high level of specialist knowledge in order to be able to provide a high level of specialist care and advice to this patient group. 5. Advice given to patients is often pertaining to deteriorating symptoms and therefore a high level of clinical knowledge and expertise is essential. Nurses and/or Allied health professionals seeking to be care coordinators should have at least 2 years experience within a critical care, neurological or neuro oncology setting. Failure to understand the potential consequences of a brain tumour patient's symptoms and/or to act upon those symptoms in a timely manner could potentially have fatal consequences.”

“1. They have 2. We did 3. There is sufficient work. Would be good to capture the private (hospital) too, although workload would be a problem 4. Not necessarily, although I believe

nursing knowledge is a definite advantage. The nurse should at least have 5 years nursing experience and good knowledge and experience in neuro oncology. RN level is fine, if they are capable. 5. Social worker, counsellor, EN, anybody with an interest and knowledge. There are different ways to approach the position and depending on your background you could tailor it to what you do best. As long as the patients are getting what they need.”

### Commentary

There is obviously a difference of opinion about the question of who should occupy such a position (nurses or other health workers), with some strong arguments being advanced. It would be a pity if that debate has slowed the development of a coordinator’s position in any specific institution.

Funding is also an issue, with the arrangements being tenuous in some instances. Overall, there is strong support for the concept from among staff who have frequent contact with brain tumour patients and their families. There is an underlying issue of whether or not the duties could be combined with responsibilities for other cancers. It appears that some of the functions envisaged for the position are now being undertaken by other staff, who often have limited capacity to expand that role.

### Question 6

Question 6 sought information about care coordinators for other cancers in the respondent’s treatment centre and also whether or not they had applied for funding for a brain tumour care coordinator.

By this stage of the survey many respondents had already indirectly answered these questions but some extra information did come to light as indicated below.

### Other cancer care coordinators

Breast, haematological, GI, urological, head and neck, bowel, upper GI, gynaecological, prostate, AYA, lymphoma, sarcoma, melanoma, ENT, BMT, pancreatic, solid tumours.

Many of these positions, except breast, are shared or are part-time.

### Brain tumour care coordinators – funding – unsuccessful applications

A common funding process for the brain tumour positions was to commence with a one-year grant for a pilot project (on one occasion called a “research project”), funded by an internal or non-hospital source such as a cancer institute, and then to move to a more fixed basis, either funded internally or from other sources as the service proved its worth. One respondent commented: “not actually sure where this soft money (for the pilot project) came from – probably scrounged together from a variety of sources”. Another commented: “the rest of the money has come by diverting research grant money – which meant that I did the research on weekends to make up for it”. Two positions received one-year partial funding either for pilot or permanent positions from separate pharmaceutical companies.

Many respondents did not know if their centre had ever applied for funding but others responded “Yes, insufficient caseload”; “Never applied, been told there is no money”; “Yes, through XXXX funding – most likely failed as the money provided through XXXX is not for provision of any clinical services”; “Probably never applied because of lack of knowledge re who to apply to and then finding the time and energy to make the application”.

### Question 7 – Leave

Question 7 asked if the brain tumour patient coordinator’s position was filled when the occupant was on leave.

From the overall responses one gains the impression that support for the patient via the replacement arrangements would be confined to very basic issues. Comments included:

“Another nurse takes the calls--they then contact me-or the coordinator by email or text- wherever we are in the world for advice-- we are acutely aware that this is not sustainable-and need to train others-I am aware our coordinator diverts the work number to her mobile-and this resulted in a call xmas day--unfortunately these patients go through periods when they need support 24/7 and panic when we are not around-“

“The role has been filled for emergency calls only by another RN who has experience in neurosurgery. When this has not been available the nurse has left instructions at the practice and on voice and email to advise patients and families with the line of emergency contact during the leave period.”

“All of the tumour-specific cancer nurse coordinator positions in XXXXX are covered by others with their own full time load in their own tumour stream. There's not actually any leave relief.”

“For our leave as care coordinators, we put out an expression of interest at the beginning of the year. It was open to nurses and allied health staff. They had to submit a cover letter and resume and then we interviewed. We selected the top 4 or 5 applicants who then formed our 'leave pool'. We went down the list starting from the top applicant when leave became available. This was a great way for others to get to know the job and for increasing team relationships.”

“This is very difficult. In the past the Cancer support nurse would provide some backup... but now nothing.”

“But depend upon length of leave - generally needs to be 2 weeks or more.”

“No replacement for annual leave or sick leave. Limited service coverage by other cancer service staff such as McGrath Breast Care Nurse or Oncology Social Worker.”

“The cancer care coordination positions are not replaced when the incumbent goes on leave. The two full time people will carry the others pager and assist where possible.”

“When people relieve in my job ie I am a Neurosurgery Case Manager, people have trouble coping with the workload so brain tumour slips. The Neurosurgery registrars fill the gap but not in a comprehensive way.”

“Leave cover for the full time FTE position is phone cover only, due to a current lack of staff funding for leave cover. Other usually clinic and ward attendances are not covered, unless the .3FTE is working those days.”

Commentary: The journey for someone with a malignant primary brain tumour can be as short as twelve months\*. If the usual occupant of the brain tumour coordinator’s position is absent without replacement arrangements for any period longer than, say, two weeks, then the patient and their caregiver/family could easily feel marooned. Do some of the unsuitable leave replacement situations revealed in the above quotes stem from an overall inadequate staffing situation in cancer care, or a lack of priority for brain tumour patients when managers are faced with competing demands?

#### Question 8 – Access to supporting documentation

The final question, apart from that seeking the respondents’ contact details, asked if respondents had access to business plans etc that might be relevant to an application for funding for a brain tumour care coordinator’s position and if they were prepared to share that information.

All who had plans were willing to share them, some needing to seek prior management permission. There was also an indication that some sharing had already taken place. One respondent commented: “We are not good at admin speak but do have some info that might help”. BTAA would be happy to transmit requests for such material on behalf of those seeking to draft applications.

Commentary: A cancer service or a philanthropic organisation with access to skilled professionals could perform a useful public service by developing an application template for a brain tumour care coordinator which could be refined to accord with local circumstances and practices.

Conclusion: One of the benefits of participating in a cancer clinical trial is said to be the opportunity it presents for a closer monitoring of the patient’s progress\*. This is sometimes achieved by the investigator having a nurse allocated to the trial who acts as a reference point for participants, particularly in regard to the reporting of adverse events. In a sense, these nurses act as informal care coordinators, at least for the duration of the participant’s active involvement in the trial. In Australia the problem is that our population is dispersed and most brain tumour trial investigators are located only in the major population centres. Payment for trial staff can also become a competing demand on financial resources, unless the funding is sourced externally. Unfortunately, brain tumour patients cannot rely only on these staff members to meet the continuous support needs that are evident from responses to this survey.

Another issue in the funding area is that because of the low incidence of brain tumours and often devastating outcomes there is not an easily reachable and identifiable community pool of

survivors and families who may constitute a source for major fund raising as occurs with, say, breast cancer and prostate cancer.

It is noted that some hospital and cancer organisations have featured paediatric brain tumour patients in their fund-raising or awareness-raising campaigns, in realisation of the ‘pull’ of childhood cancer images, but the evidence from this survey is that the need for brain tumour care coordinators is greater in the *adult* area and it could be interpreted as being inappropriate to use such images when the purpose is mostly intended for specific expenditure on a service for adults.

Furthermore, one of the strongest “selling points” in brain tumour awareness raising revolves around the poor prognosis, comparatively poor five-year survival, and potential years of life lost by those who are attacked with the disease\*. BTAA, as the only national patient and caregiver advocacy group, has recognised this problem and has tended to avoid concentrating on these statistics in public statements because of a belief that their emphasis and repetition will impact badly on the sense of hope held on to by many who are living with a brain tumour.

A common experience is that of a family which has been devastated by the loss of a loved one from a brain tumour and wish to do something to ensure that fewer families experience what they have undergone. A brain tumour care coordinator’s position in one of the States is actually funded from a memorial trust established for that purpose. In another instance, Mr Steve Newton and his family from Sydney provided the funds for the development of the first clinical practice guidelines for Glioma as a tribute to his late wife Valerie (Guidelines 2009). That funding was facilitated by an oncologist familiar with the needs of the brain tumour community.

To cater for these altruistic wishes Brain Tumour Alliance Australia undertook a survey during 2010 of charitable organisations with a relevance to brain tumour research and has uploaded to its website a spreadsheet with descriptive and contact information for these bodies (see: <http://www.btaa.org.au/BTAASurveyConsolidated.pdf>) . Potential donors seeking appropriate research institutions are pointed in the direction of that list. BTAA itself has deliberately avoided seeking tax deductible status because of the belief that there are already sufficient organisations active in this area.

A threshold question which has never been resolved is that there are often competing demands in any cancer community: education, research, treatment and care, advocacy, and raising community awareness. What emphasis should be allocated to each component? Has the care and support role been neglected? In cancer control generally, is there now a relatively disproportionate emphasis on healthy lifestyle, early detection, screening and prevention of cancers, at the expense of the traditional functions of support? For brain tumours this is particularly relevant because they are generally unpreventable and cannot be detected early, nor are they influenced by lifestyle or eating habits.

Those who have recently and unwillingly been inducted into the brain tumour community soon realise that the advent of the Stupp protocol in 2005 represented the first major advance in brain tumour treatments since the demonstration of the benefits of radiation therapy almost twenty-five years earlier. (Stupp et al 2005). This fosters the belief that the search for a cure will surely be achieved by more research and funding for research and that efforts in the past must have

been lacking in some way. No one has asked the difficult question – is that research likely to take place in Australia, or is it more likely to occur in the research laboratories in the USA, Europe and Japan? The contrary argument is that while the breakthroughs might not occur in Australia, investment in research leads to the development of important skill sets among Australian researchers.

The fundamental finding of this survey is that among patients, caregivers, family members and the professional staff who deal with brain tumour patients, there is believed to be a significant unmet need for more brain tumour care coordinators – not necessarily full time practitioners but at a FTE level related to the needs and volume of patients attending each cancer treatment centre.

How then might this need be met?

The several care coordinator positions that do exist have shown that they fulfil a need. The diversion of internal funding or its raising from external sources underlines the need and usefulness of this service, particularly when it has been instituted and maintained in a private service delivery unit. The Federal Government has demonstrated that it is prepared to intervene in cancer funding when it has been convinced there is a need. Funding should be made available by the Federal Government for the financial support of existing brain tumour care coordinator positions and for the creation of extra positions, possibly of varying FTE levels, in treatment centres where there is interest and support.

Supplementary funding could be sought either from within local health services or from within the community. It is not an impossible objective – in an Australian city with under half a million population, over \$70,000 was raised for non-specific brain tumour research from a fun run held during 2010. Even \$20,000 raised repeatedly on an annual basis would help to underpin the position of a brain tumour care coordinator for that local cancer service but we must also acknowledge that because of the relatively low incidence of brain tumours in the community a sufficiently large enough funding base will not always exist in all communities.

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## APPENDIX A

### Text of the survey sent to BTAA contacts and others.

**Background:** The journey with a brain tumour can be a major challenge for everyone concerned. This survey represents a "snapshot" of the number and role of brain tumour cancer care coordinators in Australia, and the need for such people, and is for the purpose of assembling information *in a de-identified format* in response to the Federal Treasurer's invitation for the public to recommend projects for funding in the next Federal Budget.

The originator of the survey, Brain Tumour Alliance Australia (BTAA), is the only national brain tumour patient and caregiver organisation in Australia.

Question1 **Occupation/Interest**

Brain tumour patient/survivor

Caregiver/Former caregiver  
 Family member  
 Neurosurgeon  
 Radiation Oncologist  
 Medical Oncologist  
 Nurse  
 Allied health professional  
 Other health worker  
 Interested member of the public

**Question2:** Are you a brain tumour cancer care coordinator *or do you know of one*? If yes, please give the work title for the occupant and their name and email address so that we can seek further information from them for this survey.

2

Additional Comment

**Question 3: Title:** What is your preferred title for the type of occupation being considered in this survey e.g. brain tumour cancer care coordinator; brain tumour care coordinator; system navigator; brain tumour patient assistant, other title?

3

**Question 4: Please answer these questions only if you are a patient/survivor or caregiver/former caregiver -**

(1) During your treatment were you invited to contact a specific staff member (other than your specialist) for on-going assistance in navigating the health system and in answering treatment questions of a non life-threatening nature?

(2) Could you contact this person after office hours? If yes, was this person available for all aspects of your treatment (e.g. neurosurgery, radiation therapy, chemotherapy) or were they associated with only one treatment service?

(3) Did you "share" this contact person with patients receiving treatment for non-brain tumours, or were they allocated exclusively for the assistance of brain tumour patients?

(4) Did this person have sufficient knowledge to deal with your enquiries and did their assistance make the journey easier for you.

(5) If you did not have access to this assistance, would you welcome its introduction?

**Question 5: Please answer these questions only if you are a specialist, nurse or other health worker -**

(1) Would your work area welcome the capacity to create and fill a position of a dedicated brain tumour cancer care coordinator?

(2) Have you sought to create such a position?

(3) Would there be sufficient work for a brain tumour care coordinator, or should the occupant also assist people with other cancers? If so, what cancer area(s) do you regard as providing an appropriate synergy?

(4) Should the position only be occupied by a nurse? If so, what level and qualifications should the occupant possess?

(5) If not, what qualifications and experience should the occupant possess and what other professional categories might be suitable (e.g. social worker)?

**Question 6: Please answer this question only if you are a specialist, nurse or other health worker -**

(1) Does your cancer service provide dedicated or shared care coordinators for other cancers? If yes, for which cancers?

(2) How many care coordinators?

6 (3) Are they dedicated to specific cancers or shared across cancer groups?

(4) Has your cancer service ever applied for and failed to obtain funding for a brain tumour care coordinator? If so, why do you believe the application was rejected?

(5) If you have successfully received funding from a source external to your main service provider, what is the nature of the source and is the support intended for continuous funding, or only as a "pilot" project?

(6) If funded internally, is the funding continuous, or only as a "pilot" project?

**Question 7: Leave replacement:** Is the position of the brain tumour care coordinator you are familiar with, either as a patient, caregiver, or health professional, filled by an appropriate temporary replacement when the usual occupant takes leave e.g. annual leave, maternity leave, etc.

7

Additional Comment

**Question 8: Resource materials:**

(1) Do you have access to business plans, past applications for assistance, job descriptions, and draft budgets which might assist other cancer services in initiating an application for funding for a brain tumour cancer coordinator's position?

8

(2) Are you willing to share these materials on a one-to-one confidential basis?

**Question 9: Respondent's details:** This is for the purpose of Brain Tumour Alliance Australia contacting you to obtain clarification or further information. Your personal information will not be passed on to the Australian Government when we draw upon these responses to draft a case for Federal funding.

## APPENDIX B

Results for a similar question asked by the IBTA of its international contacts (mainly UK, USA, Canada, and Australia) in late 2010.

(NB The numerical sequence of responses has been maintained with the deletion of irrelevant or nil answers.)

**Question.** Do/did you have access to a dedicated brain tumour care co-ordinator who acts as a point of contact to assist you with navigating your treatments and is available to answer questions of a non-emergency nature? If yes, please advise in the comments box any additional

information about this service e.g. was the care co-ordinator a specialist nurse, social worker, or other health service person? What is their title? Were they available after hours?

- 1 All of the above with a neuro-oncology doctor on call 24/7
- 3 Specialist nurse. Not available after hours.
- 5 My son's doctor has done this as have the nurse practitioner and the nurses.
- 6 Their now is a BT Navigator in Halifax that is very helpful.
- 7 not sure that I need one at the moment but I do know there is now a "brain tumour nurse" used for much of the above.
- 8 I don't have anyone for dedicated brain tumour care. I had a district nurse, personal care. When I was on chemo the oncology department was available 24hrs if I was sick
- 9 After surgery, (and retirement from the military), I found my own NS who now follows me
- 10 Not till we changed hospitals and researched this. We changed to a hospital where this was available. The Wesley.
- 11 I found a local organization Fighting Chance based in Sag Harbour NY that was able to help me with paperwork for disability, finding local doctors who take my insurance and psychological issues.
- 12 In 2005, there were no 'Clinical Nurses' to assist us. This came about in 2008. As MNG, rose from 21mm to 28mm, we were sent to an Oncologist for opinion. He showed concern why our situation had taken 2.5yrs for action review!
- 13 But she had too many patients to deal with and could not dedicate enough time.
- 14 My primary physician played that role, and very helpful on a couple occasions while hospitalized.
- 15 Doctors are fantastic, but other local Brain Tumour group consists of local patients who meet up monthly as friends - very informal. No formal health service group available. I know there is a Cancer Council group in XXXXX, which we can phone, but I have not done that as yet.
- 16 No. I am appalled at the lack of consistency of care/information in XXXXX. The local social worker/coordinator's role seems to be travel advisor for sending patients interstate for treatment.
- 18 We have a contact nurse in the neuro-oncology program who acts as a point of contact. She isn't available after hours but we would just page the on-call fellow for after-hours emergencies.
- 19 I wish that I had
- 20 Our's is a PA, sees patients on her own and backs up our NO. She comes to some of support group meetings as well, to understand our concerns outside the purely medical.
- 21 Not once did I meet with the Head Surgeon!! never saw her!
- 22 MD himself
- 23 During my clinical trial of the investigational drug mifepristone for progesterone receptor related meningioma I have been carefully monitored by my doctor
- 24 Clinical Nurse Specialist XXXX has a telephone service. Not available after hours although there is a 24/7 Neuro on call if emergency
- 25 The coordinator during diagnosis was a neurologist. During treatment it was the neurosurgeon. After one year I was transferred again to the neurologist for the follow up.
- 26 Yes, my neuro-oncologist
- 27 Supervisor of Rad-Onco XXXXX and Chief physicist XXXX of the XXXX
- 28 This would have been helpful. A neuro-oncology nurse specialist
- 31 oncology nurse for non emergency contact but not really any other help
- 32 a nurse provided by Anna's Hope. Available during normal hrs. Specialist neuro oncology nurse

- 33 I use my oncologist contact at the national cancer hospital for this, he has polyclinic service one day a week.
- 34 The nearest brain tumour care centre was in Toronto, 1300 km away from our residence. The nearest regional general cancer centre was 300 km away. We boldly contacted experts across Canada and in the USA and Germany, by email and telephone, manipulating access to and responses from them with 'Dr', since both XXXX and I have PhD's. However, the family physician, radiation oncologist and neuro-surgeon (in Toronto) were mainly critical in effectively getting things done.
- 35 specialist nurse
- 36 pipe dream! even for other cancers...
- 37 Specialist hospital nurse extremely good and supportive from first meeting.
- 38 Specialist nurse. Not available outside working week
- 39 nurse practitioner will call me back with answer to my question.
- 40 Usually I make a call to my neurosurgeon. We do not have this service as the brain tumour care co-ordinator or etc. But that would be very great.
- 41 we have a neuro-oncology nurse that can be contacted by patients on a low-threshold base
- 43 I can contact my oncologist anytime. I take care not to misuse this privilege.
- 44 Again, our local hospital was ill equipped to deal with brain tumours but acted like experts. They refused to work with Duke where my mom had her surgery. They were arrogant and uncaring.
- 45 XXXXXXXX at the XXXXXXXXXXXX Brain Tumor Centre was ALWAYS available to help and is an extraordinary person
- 46 specialist nurse 4
- 7 but his role was really taken on by mum's neurological oncologist XXXXXXXX.
- 48 No, no and no. Since then one practice has adopted that approach and patients of that practice now have immediate contact when required - brilliant and necessary.
- 49 No one was ever available to offer dedicated advice on Brain Tumour care
- 50 At the start but she went on extended sick leave and no contact since.
- 52 Oncology Nurse Specialist - out of hours we had a number for the Oncology bleep-holder if required.
- 53 There are nurses and a social worker and others we met with upon first undergoing treatment. The nurses always get back to us, but since the chemotherapy is being administered by a local oncologist there are some times where the nurse at the brain tumor center will tell us to ask the local oncologist. The local oncologist is not specialized and gives different answers than the specialist so we prefer to ask the neuro oncology staff, so sometimes we have to request that the nurses at the brain tumor center not refer us back locally.
- 54 it was me...the caregiver
- 55 Did not need one.
- 56 Once we had care in place at XXXXXXXX we had a wonderful 'research nurse'. As far as I remember she was not available out of hours.
- 57 There is little to no support for brain tumour sufferers.
- 58 I am not sure of what their titles was, but there was two gentlemen available all hours and they assisted my surgeon they were-responsible for coordinating all of the patients care and treatments
- 59 The nursing team at the UCSF brain tumor center is very helpful and available during all business hours for questions.
- 60 This would be a fantastic initiative and an enormous support.

61 They were a Paediatric outreach nurse specialist in neuro Oncology this service no longer exists

62 Two special nurses. Title is Consultant nurse for children with brain tumor. Available weekdays.

63 Macmillan nurse with personal experience of brain tumour, the specialist neuro-oncology nurse was not as helpful

64 doctor's assistant and nurse

65 Care co Ordinator, has massive job, I know she's there, haven't needed to bother her so far,

66 But that would have been wonderful!

67 No. Not at all. Absolutely not.

68 There was no specialist nurse and I was not directed to any patient help service where I was treated.

69 We had several people we could contact. We could call my husband's oncology nurse, we had his oncologist's cell phone number, we could email doctors and the hospital also had an after hour answering service that could answer our question. Over the years of his diagnosis we used all of these resources to get answers to our questions.

70 During the medical treatment and after the end of therapies there were/ are many specialists who had/ have always time for me if I wanted/want to talk about my tumour and everything else.

71 MacMillan Nurse seconded to the Oncology team at the Hospital particularly for this role. Not out of hours though.

72 Nothing was available

73 at our institution

74 There is an oncology co-ordinator at XXXXXXXX Children's hospital who we are connected with but I find it difficult to get in touch with her and definitely not after hours. I don't believe she is a qualified health service person.