



BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.
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HEAD TO THE HILL

Stronger Together

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THIS MAGAZINE WAS PRODUCED WITH THE ASSISTANCE OF DONATIONS

CHAIR'S REPORT

Stronger Together

For many years the Brain Tumour Alliance Australia has worked to provide the very best possible outcomes for brain tumour patients carers and their families across the nation. The BTAA provides:

Support	we support the needs of Australians affected by brain tumours through our services such as our 24/7 Support Line, support groups
Information	we develop and provide high quality information in a range of formats including our monthly e-news, magazines, and comprehensive information on our webpage
Representation	we advocate on behalf of Australians affected or at risk of brain tumours to ensure their voices are heard, and for improved care and research
Connection	we connect people and organisations in the brain tumour community

Across the nation there are many great organisations that have worked with us informally to improve support for brain tumour patients. Some of these have had a regional or city based focus, others have focused on research and fund raising for research, while others have tried to address particular tumour types and age groups. Some areas of the country, including major cities and many regional areas, still have limited support services at hand.

One of our goals has been to ensure better connection between all of the Australian brain tumour organisations, so that we can work together and provide stronger and more universal support to those affected by brain tumours. During 2022, the BTAA provided some seed funding, from our limited resources, to establish a brain tumour peak body called the Australian Brain Tumour Collaborative group. Nearly all Australian brain tumour organisations have now joined.

Almost immediately after the ABTC was established, and after only a few inaugural meetings, the group was faced with an issue that could be life changing for those affected by a brain tumour.

The eligibility for brain tumour patients experiencing extreme disability for inclusion on the National Disability Insurance Scheme was brought into question. The changes to eligibility were designed to reduce the overall cost of the NDIS to the government, but this meant that these patients may have been left without the day to day assistance they needed, and that this burden would fall instead on already stressed family members.

The ABTC was able to work effectively with the highest level of the Australian Government to achieve recognition of the unique issues faced by brain tumour patients. A full report on the negotiations is included in this magazine. While more negotiations on this matter will continue, members of the brain

tumour community can be reassured that the ABTC group will effectively represent their interests and that working "stronger together" will ensure our voices are heard into the future.

Special mention must be made of the significant advocacy we have had from Senator Catryna Bilyk and her adviser Paul Metcalfe. The demise of the disabled in our community would have absolutely been cemented, if it was not for the support they have given.

The ABTC has also been working extensively to ensure that the Australian Cancer Nursing and Navigator Program, which has funding of \$166 million and will provide 100 nurses, provides adequately for the needs of brain cancer patients in an equitable way based on their needs. This is essential so that the unique issues faced by brain tumour patients are recognised and given proper consideration.

While all of this important high level advocacy is taking place it is worth noting that our day to day work of supporting and informing brain tumour patients continues at full speed. Our team of volunteers who staff our 24/7 Support Line, lead support groups, organise patient forums, maintain our extensive and up to date online resources, and produce our publications, are all patients, former patients, carers or family members who devote their time to support other brain tumour patients and I would like to thank them all for their efforts over the year.

The BTAA is a small organisation with a national reach. We run on a very small budget and do not actively fundraise as we must concentrate on providing support to those affected by brain tumours. Our income comes from individuals who make generous donations, have fund raising events such as dinners or morning teas, or undertake "go fund me" activities. A special thanks to all of those who have contributed recently.

Craig

**Craig Cardinal
Chair**



Craig's wife, Berlinda, was diagnosed with high grade brain cancer in October 2015. Craig joined BTAA after years of experiencing and witnessing the struggles of brain tumour survivors, families and carers whilst navigating services and supports in Australia.

Craig spent close to 30 years with defence and served in the Royal Australian Air Force, Royal Australian Navy and as a public servant with the Department of Defence. Craig also served with the Australian Customs and Border Protection Service and has consulted and contracted to industry, state and Commonwealth governments.

Craig is passionate about contributing to the improvement of services and supports for brain tumour sufferers and families.



“Head To The Hill” To Be An Important Annual Event

During November 2023 the inaugural Head to the Hill Brain Tumour Awareness event was held on the lawns of the Australian Parliament House. The event was a great success, as more than 300 people attended to see the display of 1600 empty shoes to represent the number of people who die each year from brain tumours. Hundreds of impact statements were collected and presented to Senator Catryna Bilyk. The shoes were collected from the community, and we asked for short bios to be provided with each pair of shoes so that those present could wander amongst the shoes and feel the stories of those affected come to life.



As the Parliament was sitting in both houses, a number of politicians also attended and the event was well covered in the print and television media. Speeches encouraging the work of the BTAA and other support organisations were made by Senator Catryna Bilyk and the Assistant Minister for Health and Aged Care, Hon. Ged Kearney MP. Many federal members also supported the event, as we encouraged the community to write to their local members and describe how they have been impacted by brain tumours in their families.

Many patients and their families attended from across the country, with Head to the Hill serving as both a recognition of the suffering of those with a brain tumour, and a memorial for those lost. Diane Dunn, the Secretary of the BTAA, was the driving force behind Head to the Hill and should be congratulated on her hard work and persistence in coordinating this great and significant event. BTAA committee members also worked tirelessly to manage each aspect to make the Head to the Hill so special.

Although a relatively rare cancer, survival rates for brain cancers are low and it remains the biggest killer of children than any other disease, and the leading cause of death from cancer for people under 40. Survival rates for brain tumours have not improved in the last 30 years and the economic costs are higher than any other cancer.



"The hidden tolls of brain tumours are felt in every city and town across Australia. The disease does not distinguish between rich or poor, city or country people and has a devastating effect on patients, carers and their families," says Craig Cardinal, the Chair of the Brain Tumour Alliance Australia, that led the event.

"Survival rates have not increased significantly in thirty years, remaining in the low 20% range. It is shocking to realise that brain tumours kill more children than any other disease, and possibly more than any other cause, including accidental death. The ongoing cost to families, community and the country is huge," said Mr Cardinal.

Each year around 1,896 people are diagnosed with a brain tumour and more than 1,528 die from the disease, (Australian Institute of Health and Welfare 2021. Cancer data in Australia. Cat. no. CAN 122. Canberra: AIHW). Brain cancer kills more children in Australia than any other disease. (Causes of Death, Australia, 2019. Australian Bureau of Statistics, Australian Institute of Health and Welfare 2021. Cancer data in Australia. Cat. no. CAN 122. Canberra: AIHW).

Brain Tumours

1528

**Australians
die each year**

Brain Tumours

1896

**Australians
diagnosed
each year**

Brain Tumour Survival rates

**No real
improvement for**

20 Years

Brain cancer survival rates are low and have hardly changed for 30 years, despite significant increases in survival for Australians diagnosed with other types of cancer, such as prostate and breast cancer. (Australian Institute of Health and Welfare 2021. Cancer data in Australia. Cat. no. CAN 122. Canberra: AIHW). The five-year survival rate of prostate cancer has increased from 60% to over 90%. Breast cancer survival has increased 72% to over 90%. The 5-year survival rate for brain cancer has increased from 21.2% in 1986, to only 22.3%. For some types of brain cancer, survival is much lower. For glioblastoma, the most common primary brain cancer in adults, only 5% of people survive 5-years post diagnosis. (Australian Institute of Health and Welfare 2017. Brain and other central nervous system cancers. Cat. no. CAN 106. Canberra: AIHW.0)

The financial cost of brain cancer, to both patients and society, is the highest of all cancers (CanTeen Australia 2017. The economic cost of cancer in adolescents and young adults). Brain cancer costs more per person than any other cancer because it is highly debilitating, affects people in their prime, and often means family members cannot work if they become carers. Brain cancer has the highest total burden of disease for adolescents and young adults in Australia, with a cost of \$1.7 million per person. (CanTeen Australia 2017. The economic cost of cancer in adolescents and young adults).

The Head to the Hill event will be held in **November/October** each year - timed to coincide with International Brain Tumour Awareness week and when both houses of Parliament are sitting to ensure maximum participation from politicians. We expect it to grow in significance and importance. If you wish to be involved in organising this important event, contact us at enquiries@btaa.org.au. Keep a close eye on our web page and e-news for details of the 2024 Head to the Hill.



Brain Cancer

22.3%

**Five year
survival rate**

Glioblastoma

5%

**Five year
survival rate**

Brain Cancer

kills

**more children
than any other
disease**

How does your tumour grow?

By Kate Bown

With curling tendrils of brilliant blue,
an impossible creature
fathoms deep inside
you.

Would you pick it for me?
Hold the stem slowly,
plunge your nostrils,

Perhaps it glows?
With fruiting spores iridescent green,
a tiny jewel of the forest
popping out of the peat,
unseen.

breathe
the sweet subtle melody,
the sound of the sun
warming the petals.

Maybe it oozes?
With bulging bodies of egg-white,
a compost heap species
slipping under a rhubarb leaf
at night.

I never wanted a rose in my garden.
Now I grow one in a pot.

Or rises in the gloom?
With fizzing bubbles of nebulae-gas,
a ball of dough on the bench
fermenting within dark glutenous
threads.

Do you ever wonder
what's growing in your head?

Does it smile?
With blazing orbs of organic matter,
a dandelion shoot in the tangled
grass
waving a yellow flower, an unrequited
treasure.

Or sing?
With trilling octaves at first light,
a common migratory species with
black feathered wings, a mate
for life.

And what if it grew like a rose,
like the one inside my head?
With spiralling petals of pink
marshmallow,
a fluffy cloud in a summer sky,
a watercolour dream,
an angel's pillow.



'Rose' by Lottie Bown, 9 years old.



Writing my brain tumour journey

In 2013, I was diagnosed with a Rosette-forming Glioneuronal Tumour of the Fourth Ventricle (RGNT). Like so many of you reading this magazine, my brain tumour journey was catastrophic.

Yet here I am, striding forward into my twelfth year. Not shattered. My time not up, just yet.

There are days when I feel vulnerable, like a spider web strung between the branches of a tree, swaying in the breeze, waiting for a rush of air, or a clumsy hand, to sever it. And I am apprehensive of what may be ahead.

But I go anyway. I want to endure.

A few years ago I began writing — about my life and survivorship, about finding hope and joy. The process of writing can be challenging, but I enjoy the quiet attention and the love of life it demands.

As poet and novelist Peter Goldsworthy wrote in his 2024 cancer memoir — *The Cancer Finishing School* — 'Writing is life-affirming, an illness like cancer is not'.

And you? Do you have a story or a poem about your journey you would like to write?

Kate is a mother, brain tumour survivor and BTAA Committee member. She lives in Tasmania with her husband and four children. She writes stories about family life and survivorship at wildandwonderful.substack.com

National Brain Tumour Supports

The NDIS and State of Play

Brain tumour patients, family and friends do it very tough – and have done for too long. The volume and types of complexities and challenges faced by our community are significant and are often misunderstood – including by governments.

Patients and families navigating through the mainstream and allied health systems without specialist nurse support coordinators and attempting to access disability supports such as the NDIS makes the survivorship journey very strenuous.

NDIS – changes and impacts

The National Advocacy Service (NAS) is managed under the Peace of Mind Foundation and funded by the Cure Brain Cancer Foundation. It is a service that was implemented in November 2021 with an aim of providing free national support to brain tumour patients with a core aim of connecting patients and families to supports community, mainstream and commonwealth supports - including the NDIS.

In around August-September 2023 the NAS noticed an almost a drastic change in NDIS applications approval rates for permanently and significantly disabled brain tumour patients – going from close to 100% approval rate to close to 100% rejection rate.

The devastating impacts to patients and families were immediate. Stories of horrific hardships - adding to an already very challenging period - because of no access to the disability supports was resounding.

Awareness

The Australian Brain Tumour Collaborative (ABTC) comprises of a steering committee representing eight national brain tumour support foundations. The ABTC was funded by BTAA and was implemented to provide the crucial united national voice to government and to seek much needed change for our community.

The ABTC engaged with government to begin raising awareness of the issue and to seek an immediate reversal.

In September 2023, the ABTC and the NAS met with Minister Bill Shorten, Senator Catryna Bilyk and NDIA senior executive leadership. The presentation to government highlighted the plight of brain tumour patients and their disabilities, the impacts from rejection to access the scheme and patients legislative right for NDIS supports where the patient was entitled access.

The Minister directed the NDIA to work collaboratively with the ABTC and NAS to understand the issue and seek to resolve.

Since this initial meeting there has been continuous engagement with the NDIS, Minister and Senators and advisers. This has been a particularly tough period as the responses have been slow with no initial clear understanding of the reason for the change.

NDIS and Palliative care.

One of the core reasons for the implementation of the NDIS was to provide a national centralised scheme for people with disabilities. This required agreement between the States and the Commonwealth with the commonwealth taking prime responsibility for disability supports at the national level. This meant the states would mostly – but not completely - relinquish their main disability supports and provide funding to the commonwealth for the national scheme.

The agreements between the NDIS and the States needed to describe roles and responsibilities for various services. This agreement was formalised through a Table of Supports between NDIS and other Supports.

One portion of the Table sort to describe the responsibility of NDIS for disability and the role of the State for palliative care.

The intent of this portion of the Table was to ensure the delineation of service when people with disabilities being supported through NDIS also needed to access State based palliative care support.

Prior to August 2023, brain tumour patients accessing NDIS and palliative care concurrently had never been problematic. Both NDIS and palliative support services had supported patients harmoniously for their respective support needs – if required and if they met access criteria.

Changes and Reasons

The NDIA had made an internal policy decision to change the way they assess people with potentially life limiting diseases – particularly high grade brain cancers. The intent of the unannounced change was to deem high grade brain cancer patients as palliative – and, in doing so, push responsibilities for brain cancer patients disability supports into mainstream palliative care supports.

Clearly, mainstream palliative care and NDIS disability supports are very different services. Almost every brain tumour patient – apart from occasional low-grade patients – were rejected. The despair and horrendous challenges now faced by people most in need of disability supports was immediately felt.

In essence, the reason provided by the NDIS rejecting high grade brain cancer patients was due to a clause under Section 24 (1) of the NDIS Act. This principally stated that despite being permanently and significantly disabled, your support requirements are better off serviced by mainstream palliative care.

Despite key national palliative care bodies such as PalCare Australia advocating on our behalf, the NDIA continued to reject patients.



Current State

The ABTC and NAS have been engaging with the NDIA/NDIS and government continually in both an operational and strategic context. There has been almost daily engagement with the NDIS executive team and regular engagement with the Senator and Minister offices.

As of mid-March, patients who would have until recently been rejected are now being accepted again. It has taken an incredible amount of work to advocate for the change in access assessment to be reversed.

Advocacy

There are many people fighting with us to help our needs be understood. Groups of neuro-oncology specialists are fighting to ensure drug supplies for our patients are sufficient.

Brain tumour specialists are coming together to help develop an education program highlighting disease, treatments and impacts for the NDIS.

Senator Kovacic is questioning the government and department on brain cancer issues in the Senate.

The Minister and staff are working to address the issue.

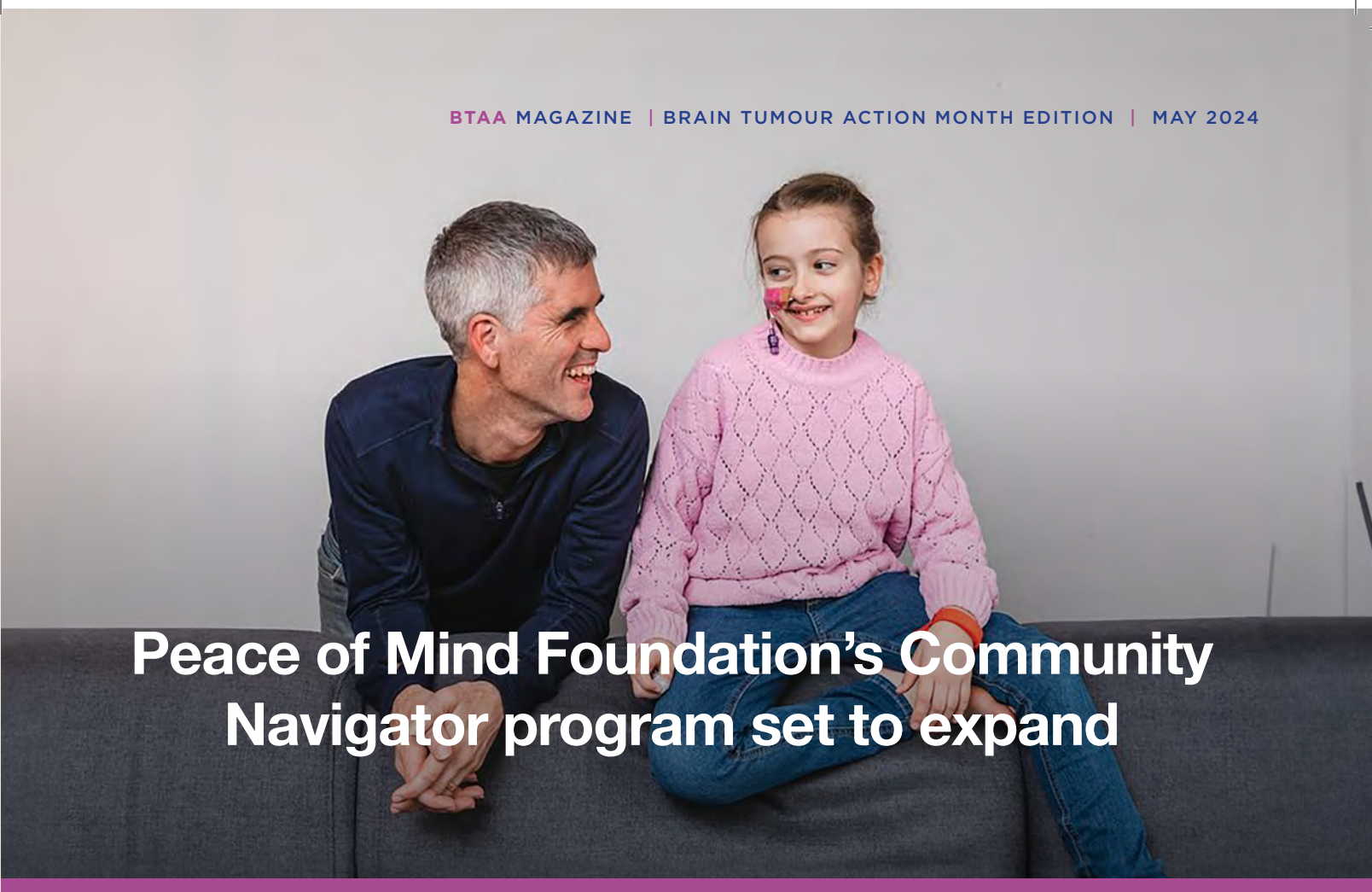
The NAS (Fiona Hassman and Team) are working hard daily to represent our patients with NDIS access and plan management teams.

NDIS/NDIA senior executives – particularly, ‘Cassie’ and ‘Helen’ and their teams in Scheme Eligibility Branch – have shown outstanding leadership, commitment, and compassion to work through the challenges and provide solutions. Helen and Cassie and their teams are crucial to implementing a sustainable access model for our community and will utilise the education programs with brain cancer specialists to inform the future pathway.

All Australian brain tumour foundations are investing in research and/or supports.

The ABTC continues to influence government to ensure changes are national, sustainable, and appropriate for our community.

There needs to be a special mention for Senator Catryna Bilyk and her Electorate Officer, Paul Metcalfe. Their forthright and strong advocacy on this issue has been pivotal to having the government and department understand our plight and need for change.



Peace of Mind Foundation's Community Navigator program set to expand

Australia's first and only Community Brain Cancer Navigator engaged by Peace of Mind Foundation provides direct support to those impacted by brain cancer. From point of diagnosis right through to bereavement, this vital role helps patients and families navigate the complexities of living with a brain cancer diagnosis.

The program is now set to expand, with Peace of Mind Foundation announcing a new position in Ballarat/Bendigo has been given the go ahead, with plans for additional roles in the near future if funding can be secured.

Peace of Mind Foundation CEO and Founder Rebecca Mallett says the program is of enormous importance to support brain cancer patients and their loved ones.

"A Brain Cancer Community Navigator plays a vital role in the lives of those affected by this devastating disease. Navigating the complexities of a brain cancer diagnosis, treatment options, and support services can be overwhelming for patients and their families. The navigator serves as a knowledgeable and compassionate guide, helping individuals understand their diagnosis, connect with appropriate medical professionals and resources, and navigate the difficult road ahead," she says.

"They provide invaluable emotional support, helping patients and families cope with the challenges and uncertainties that come with brain cancer. By bridging the gap between medical care and community support, a navigator empowers individuals to make informed decisions and access the assistance they need throughout their journey with brain cancer."

The focus of the Community Brain Cancer Navigator is to support people living with brain cancer in their home and outside of a medical environment. The position acts as a navigator in drawing attention and priority to the current and future needs of the patient and their family and acting as an interface between the patient, the health system and service providers.

Peace of Mind Foundation's Senior Community Brain Cancer Navigator Jonathan Muller took up the role three years ago and, in that time, has worked with hundreds of families in the Barwon region, last year traveling over 26,000 kilometres to around 600 in-home visits to brain cancer patients and their families.

Jonathan's role is firmly based in community where he walks alongside families in a phase of contact which typically fall into broad stages:

1. Meeting people soon after diagnosis and navigating the initially fast-moving activity of radiotherapy and commencing chemotherapy.
2. This is followed by a lull, almost into normalcy and a period of acclimatising, often reported as feeling surreal.
3. The arrival of the dreaded MRI shows disease progression accompanied sometimes by symptoms and physical deterioration.
4. Entering the final phase of bed-based care and death.
5. The bereavement phase of initial shock and shaky re-entry to a new life without a family member.

Jonathan describes his role as one where meaningful, supported connections are formed while providing practical information.

"This role really engages the entire scope of the brain cancer journey. A key strength of the role is that it is not task driven, but instead being faithful to meet people's needs as they present uniquely in every household and at each stage of the process. I increasingly appreciate the value of the role providing a dedicated person delivering continuity of care. This capacity is unique," he says.

"I find I have an increasingly honed skill set in the real day-to-day practicalities that fall outside the scope of the health system. It is a real bonus for brain cancer patients and their families. More and more convincingly, I see the enormous benefit of being a physical presence in the household. This is difficult to put into words or categories, however it becomes more evident increasingly towards the end of life where interventions are very limited. This speaks to valuing reassurance, stability, normalcy, care, friendship, attentiveness, experience and willingness."

The role of the Community Brain Cancer Navigator is one where no two days are ever the same. As an example, a day typical day for Jonathan's may look like:

- Meeting a family for the first time soon after diagnosis to educate on their understanding and the ramifications of a brain cancer diagnosis, answering questions that were unable to be asked in the fast-paced environment of the hospital setting.
- A phone call from a bereaved carer seeking to understand death certificates and legal processes.
- Visiting a family to help identify an enjoyable activity like a weekend away. Guiding them to set a goal and assisting them with some grant money and logistical coordination to make it a reality.

- Meet a carer for a walk in the park to give safe neutral ground to talk over the challenges and realities of caring for their loved one.
- Liaising over the phone with the oncology or palliative team supplying additional information to best coordinate cares.
- On route home, drop off some basic equipment and practical pointers for mobilising around the house or making communication clearer in the household.

Peace of Mind Foundation are hoping to one day have Community Brain Cancer Navigators in every State and Territory.

"The overwhelming response from patients and families is incredibly positive with families telling us just how much of an impact having this program made to their brain cancer journey," says Rebecca.

"Our vision is to raise enough funding support for a national program because we know just how impactful it is to have this specialised service for the brain cancer community."

"No family should have to go through this alone, and the success of this program tells us that these roles make a huge difference."

Peace of Mind Foundation gratefully acknowledges the support of Hospice Foundation Geelong to the funding of Jonathan's role, with a much-appreciated contribution from APCO Foundation.

The new Navigator role is thanks to the contribution of APCO Foundation, Zoe's Fight and All About Art and support of Ballarat Hospice.

Peace of Mind Foundation is actively seeking funding partners to continue to expand the Community Brain Cancer Navigator program Australia wide. www.peaceofmindfoundation.org.au

Use the CONTAINERS FOR CHANGE App to support the BTAA

If you have collection depots in your State for refundable bottles, cans, soft drink bottles and many others with the 10 cent mark, then you can use your state Containers For Change App to support the work of the Brain Tumour Alliance Australia.

Pam Hubner of Brisbane decided to download the APP and collect containers and donate the money to BTAA. Since starting this in mid-December last year we have to date donated over \$400.00. Family, friends and others are contributing to this easy scheme. The apartment block where Pam lives agreed that BTAA would be their chosen charity given that both herself and another resident have lost their daughters to Brain Cancer.

To join in download the APP, then follow the prompts. You can help BTAA by checking what is available in your State and doing the same. Queensland, South Australia, and Western Australia have similar initiatives.

The money raised not only creates further awareness but helps fund support for brain cancer patients, carers and families. Your support will be greatly appreciated.

You can go to the Brain Tumour Alliance Australia Website www.btaa.org.au/donations to obtain the banking details required for arranging the automatic donations through the Containers for Change App.



COGNO awards prizes for Supportive Care Poster Presentations

Diane Dunn

The Cooperative Trials Group for Neuro Oncology (COGNO) awards two prizes for Supportive Care at its Annual Scientific Meeting each year. The awards are named in honour of the late Lynette Williams in a partnership with the BTAA and COGNO.

The applicants undertake some original research in the area of Supportive Care for brain tumour patients and this is presented in the form of a poster. People attending COGNO's Annual Scientific Meeting in October are able to view the research posters in a gallery at the conference.

Lynette died from a glioblastoma multiforme (GBM) in 2017. Together with her husband, Billy, they were both supported by BTAA through a local support group in Canberra in the two preceding years. A partnership with the Ghana Australia Association, where Lynette and Billy had previously lived, and BTAA led to an event that raised funds to establish a ten-year award where supportive care was the focus.

'I am pleased that Lynette's legacy includes encouraging young medical and science professionals to investigate the wider impact of brain cancer on loved ones, and to raise awareness of the importance of supportive programs that help people on this journey', Billy said in making the presentation to the 2023 awardees.



BTAA Lynette Williams Award first prize - Dr Mona Faris for her abstract "Creating a visually accessible online portal for people with brain tumour: preliminary findings".

BTAA Lynette Williams Award second prize - Ms Aleksandra Kazi for her abstract "Application of radiomics to pre-operative imaging to predict survival in people with glioma".

Sydney BTAA Support for Young Adults with Brain Cancer

Due to the different needs of younger people, and their concerns around life, social interactions, and work we have created a Chat Room under the Sydney BTAA Group called 'HeadSpace'. It will be run by those in the age group of 20-40 years with a focus on self-directed needs that will be chosen by You.

There is a recognition of doing other than medical discussions and the need for own age interaction. In this regard it will be open for you to organise catch ups and events that will appeal to you in time of day, location and availability. It will enable you to bring a support person, be that a carer or sibling, or just get there on your own using suitable transport, public or private.

There will be events published in the group and chat room such as, Pub Choir, Cafe's, Walking on the beach or in the Forest, going out as a group, meeting up in small groups or larger. All depending on what your needs are and what You as a group organise.

BTAA Facilitators will be available for online consultation and be able to answer questions as they arise / needed in organising the events.

Sydney BTAA has a wealth of medical knowledge as well and you are welcome to ask questions in the group for those that know this journey oh too well.

Please Join BTAA on the website www.btaa.org.au

and then join Facebook Sydney BTAA...

www.facebook.com/groups/BTAASYD

Emily's Story

Recently we received an email from one of our readers. It went like this:

Hello my name is Emily and I was diagnosed in March of this year. I'm a reader of your articles and wanted to submit my story. I wasn't sure if I met the criteria as I'm still on my journey. I've spent many nights putting my thoughts into words so if this isn't what you're looking for that's totally okay. I'm happy to try again once I finish my journey.

Thank you for your time.

Emily Russo

I thought I was unlucky when I developed ovarian cysts, when I had COVID twice in the same year, or all the times I'd had broken bones. I thought being diagnosed with Endometriosis and undergoing surgery would be the hardest thing I'd ever experience. I was naive.

Not even 6 months post-endo surgery would I be thrown the biggest challenge of all.

I was 27 when I was diagnosed with three brain tumours.

My case is what you might call an accidental find. The kind you hear about on a Chicago Med episode or 60 minutes. I was young and healthy, playing three sports a year, working full time, living in a nice apartment and fostering to adopt two kittens. I had a loving family and close friends. My support system.

In March 2023 I hit my head at home trying to multitask. It happened quickly and I was home alone. I remember feeling like I blacked out and being lightheaded. My memory from then was so bad it took me two days to tell my boyfriend what happened. I went to the doctor to make sure everything was alright and was shown the door five minutes later with an "all good". My symptoms grew and I went back to the practice. This time to see a different doctor. This one was thorough. He told me it would be ideal to get an MRI to rule out any inter-cranial bleeding. I remember thinking \$350... that's way too much money. I just couldn't justify that for a head knock, so I called family for support. They quickly changed my mind and I was off to an appointment that afternoon.

I had never had a brain MRI before. I'd seen medical shows of big cylinders with claustrophobic helmets and innocently based my thoughts off that. I wasn't prepared for the helmet, the cannula halfway through or the alarm inducing panic attacks. I tried to remind myself it's just a head knock and I couldn't see any bruising so I was fine.

I caught the train home after, and my phone rung. It was my doctor. "Hi Emily, I'm just calling to ask if you'll be bringing a support person with you tomorrow?" Yes of course I responded. Obviously this is normal procedure for a head injury.

The next day I was back in the doctor's room. My mind was preparing itself for good news, but I was wrong. "There was no inter-cranial bleeding, however they found a tumour in your brain, multiple tumours actually".

I felt my heart sink into the floor. My head felt removed from my body as if I wasn't a person anymore and I physically couldn't speak. The shock remained with me for a few days before I could cry. The doctor proceeded to tell me it was an accidental find, and that I never would've known if it wasn't for the head knock. Because I'd never had an MRI before, there was no timeline for the tumours, nothing to prove when they started. Questions began to grow if I was born like this, or if it was something I did. But no one knew.

I was advised a Neurosurgeon and to present to hospital immediately for further testing. The following day I was admitted to hospital. Neuro Ward, bed 17.

I thought I had died.

Over the next 7 days I experienced every emotion I could ever feel. Gratefulness of my family and boyfriend who became my support system. Loneliness after visiting hours ended. Scared of not knowing what's next.

I lost count of the amount of doctor's, Neurosurgeons and Neurologists who saw me. Each day they walked in, I eagerly awaited answers only to be met with more waiting. Days passed and the isolation grew higher. Why wasn't there a place for young people with brain tumours? My ward was occupied by people with spinal problems or the elderly with dementia, often mistaking me for a nurse. The ward was small, no bigger than a 50m circle, but I did laps every day.

I was discharged at the end of the week with no news. Multiple doctor's visits, notes being taken, tests ran, further scans done; all leading to no additional information. I was put on a wait and watch period for the next 3 months. My symptoms grew longer. I'll never forget the migraine headaches. They were so excruciating I was grabbing my head to hold it together from splitting. I began to forget days of the week and tell the same story over.

July 10 I celebrated my 28th birthday and July 12 I was admitted for my craniotomy.

I remember fighting the anaesthesia like it was my last breath. I had put all my trust in a Neurosurgeon I had met a week ago.

I woke up in ICU 4 hours later and said my first words "I need my mum". She's already on her way I was told. I questioned if I was even awake. I had 3 drips being fed into me and the strongest drugs you could imagine. Mum came in and held my hand. "I did it mum". Yes you did. Still shaking from the morphine it was hard to tell whether I came out of surgery with complications.

I spent 8 days in hospital under constant care. Mum, dad, family and friends all day and my boyfriend every night. They never left my side and taught me how to be human again. I had to learn to walk, shower, get changed and do my hair. No one knew how to prepare for an operation like mine but they all jumped into full time care. Despite many setbacks some of my favourite memories were made in hospital.

It wasn't the recovery that I found hard, it was all the waiting and not knowing. I went from a very busy lifestyle with forward-planning to living my life a day at a time. I could've told you my 5 year plan, where I wanted to live, when I wanted to start a family and get married but all of this now put on pause.

Fast forward to 6 weeks post-op I was due for my biopsy results. Of course my strongest team came with me - mum, dad, boyfriend.

Maybe this is the day I was to get good news. I had come to terms with the treatment conversation. What I wasn't prepared for was that I had a rare case. The case that would sit my multifocal glioma in 2 different grades. How could that be possible? A genetic mutation was detected and I was faced with the possibility of another brain operation. Still recovering from the first I asked is there anything I could do better? Was it something I was doing wrong?

I was put on yet another wait and watch period for 3 months.

How do you live your life knowing there's more darkness at the end of the tunnel? How could I plan for my future, save up for a house or guarantee it's going to all work out if everything's stacked against me?

My support system. I live for my support system because if I give up it would only undo everything they poured into me. All the long days and late nights, phone calls crying, holding my hand at appointments, planning trips for me to get out of the apartment, all the lifts to scans, groceries, flowers. All.

For the full transcript of Emily's story go to:
www.btaa.org.au/news/stories

- SAVE THE DATE -

Friday, 17 May 2024. 9am - 3pm

Sydney Patient Education and Support Forum

for Brain Tumour Patients

Early Registrations:

 <https://events.humanitix.com/nnog-patient-forum-2024>

Venue: Sydney Mechanics School of Arts. 288 Pitt Street, Sydney.

More information will be provided soon.

Co-Hosted by

NSW Neuro-Oncology Group (NNOG) - The Brain Cancer Group (TBCG) - Brain Tumour Alliance Australia (BTAA)



The Brain Cancer Rehabilitation Assessment Interventions for Survivorship Needs (BRAINS) Program

The BRAINS program is a \$4.9mil Medical Research Future Fund (MRFF) funded program of work aimed at delivering better survivorship and supportive care to people affected by brain cancer and their caregivers. The program will improve our understanding of the frequency and severity of symptoms and need in this population across the entire country. This understanding will then be implemented to develop improved models of care coordination for people with brain cancer and their caregivers that is responsive, timely and proportionate to the severity and urgency of individual needs.

These aims will be achieved through identification of patient and caregiver needs, models of survivorship care, information and support resources, rehabilitation, and supportive care interventions – the Five Themes of this program.

Our work is a collaboration between Psycho-oncology Co-operative Research Group (PoCoG), Cooperative Trials Group for Neuro-Oncology (COGNO), Primary Care Collaborative Cancer Clinical Trials Group (PC4), Cancer Symptom Trials (CST), community organisations, and institutions across Australia.

Further information about the BRAINS Program can be found on our website: <https://bit.ly/brainsprogram>

BRAINS Studies currently open for recruitment: Beyond Brain Cancer

We are looking for anyone aged 15-40 who has experienced brain cancer and has finished treatment that was successful in treating, controlling, or removing brain tumour to help us improve an online group-based support program. We also want to hear from carers/family members and health professional who support this population.

To find out more and sign up, click the link or scan the QR code:
<https://www.behaviouralsciencesunit.org/beyond-brain-cancer.html>

If you have any questions, please send us an email:
recapturelife@unsw.edu.au



Summaries of BRAINS Publications:

Carer preparedness improved by providing a supportive educational intervention for carers of patients with high-grade glioma: RCT results

Authors: Halkett GKB, Lobb EA, Phillips JL, McDougall E, Clarke J, Campbell R, Dhillon HM, McGeechan K, Hudson P, King A, Wheeler H, Kastelan M, Long A, Nowak AK; Care-IS Project Team

Published: Journal of Neurooncology. 2023 Jan 19.

Link to full article: [doi:10.1007/s11060-023-04239-0](https://doi.org/10.1007/s11060-023-04239-0)

What we found

A nurse-led program called Care-IS helped carers to feel more prepared to care for a family member diagnosed with high-grade glioma (HGG). The program did not help reduce levels of distress felt by carers.

Important things we learned

The Care-IS program helped carers feel more ready to take care of someone with high-grade glioma (HGG), but it did not reduce their distress or improve their quality of life. This is likely because HGG is a disease that gets worse over time and caring for someone with HGG is hard. More support is needed for carers of people with HGG in the long term.

Supportive care of patients diagnosed with high grade glioma and their carers in Australia

Authors: Georgia K. B. Halkett, Melissa N. Berg, Davina Daudu, Haryana M. Dhillon, Eng-Siew Koh, Tamara Ownsworth, Elizabeth Lobb, Jane Phillips, Danette Langbecker, Meera Agar, Elizabeth Hovey, Rachael Moorin & Anna K. Nowak

Published: Journal of Neuro-Oncology volume 157, pages475–485 (2022).

Link to full article: doi.org/10.1007/s11060-022-03991-z

What we found

In this study, we looked at the supportive care provided to people with a type of brain cancer, high-grade gliomas (HGG) and their carers. We compared supportive care to services recommended in Australia's optimal care pathways. We found that not all of the essential services are provided or available as a routine part of care for HGG patients.

Important things we learned

The supportive care provided to people with HGG and their caregivers falls short of the recommended standards, especially mental and emotional support. To improve the care of people with HGG it is essential to involve supportive care and psychosocial staff in routine care, increase access to cancer care coordinators and specialist nurses, make early referrals to allied health and palliative services, offer rehabilitation services, and recognise the role of GP's in supporting patients and caregivers in the community.

Scoping the psychological support practices of Australian health professionals working with people with primary brain tumour and their families

Authors: Tamara Ownsworth, Katarzyna Lion, Ursula M. Sansom-Daly, Kerry Pike, Eng-Siew Koh, Georgia K. B. Halkett, Mark B. Pinkham, Raymond J. Chan, Haryana M. Dhillon, for the BRAINS Program Investigators

Published: Psycho-Oncology.2022;31:1313–1321.

Link to full article: <https://doi.org/10.1002/pon.5929>

What we found

Psychological support for people with brain tumours and their families varied depending on the type of healthcare provider, where they received treatment, and stage of the illness.

Lack of coordinated care and healthcare providers' limited knowledge of brain tumours means that people with brain tumours often don't get psychological support. Some people may find it hard to access services due to the type of tumour they have or their prognosis.

Important things we learned

People with brain tumours often had effects on their brain from the cancer and its treatments. As a result, their needs are different to other people with cancer. They may need a mix of medical care, rehabilitation, disability, mental health, and palliative care services.

To improve care, there is a need for coordinated services led by neuro-oncology specialists, along with usual roles within healthcare teams. This can help patients and their families navigate healthcare and disability services and improve self-management.

Brain cancer patients' levels of distress and supportive care needs over time

Authors: Georgia K. B. Halkett, Elizabeth Lobb, Katrina Spillsbury, Haryana Dhillon, Anna K. Nowak

Published: Psycho-Oncology.2022;31:2074–2085.

Link to full article: <https://doi.org/10.1002/pon.6028>

What we found

People with a type of brain tumour, high grade glioma (HGG), have different levels of distress over time. How distressed people feel can change, for some it will be high and stay high, while for others it may start low and increase over time. Younger people tend to have lower levels of distress than older people. People who have more needs feel more distress.

Important things we learned

People with HGG experience ongoing distress. They tend to have higher levels of distress when they also have a high number of unmet needs. It is important to regularly screen people with HGG to see what their needs are and to refer them for support. Early communication about what might happen and how to prepare is helpful.

Bereavement outcomes of carers of patients with high grade glioma: Experiences of support before and after the death

Authors: Elizabeth A. Lobb, Georgia K. B. Halkett, Emma McDougall, Rachel Campbell, Haryana M. Dhillon, Jane L. Phillips & Anna K. Nowak

Published: Death Studies. 2023.

Link to full article: <https://doi.org/10.1080/07481187.2023.2167888>

What we found

Looking after someone who has brain tumour is hard. There are many complex symptoms and changes to cope with. This means caregivers need a range of supports – practical, emotional, and social. Things like having a break from caregiving and financial help are important.

Important things we learned

Carers can be better supported by early involvement of palliative care, well-delivered and more information about brain cancer, especially the prognosis and dying process.

To reduce financial stress and burden on carers they should be given information about how to get government support, respite care, and bereavement support services. The information and processes should be as simple as possible.

It is also important for to support families to talk about the preferred place of care and death. Talking about these things early in the disease process helps with planning and to ensure the patient can be involved.

Exploring the clinical utility of a brief screening measure of unmet supportive care needs in people with high-grade glioma

Authors: Rachel Campbell, Mona Faris, Joanne Shaw, Georgia K B Halkett, Dianne Legge, Eng-Siew Koh, Anna K Nowak, Meera R Agar, Tamara Ownsworth, Kerry E Pike, Raymond J Chan, Haryana M Dhillon for the BRAINS Program Group

Published: Neuro-Oncology Practice. 2023.

Link to full article: <https://doi.org/10.1093/nop/npad035>

What we found

A 9 item screening tool called SCNS-ST9 is good at finding if people with brain cancer, high grade (HGG) glioma, have care needs.

Important things we learned

The screening tool, SCNS-ST9, can pick up most of the people who have needs. This screening tool will be useful in clinical practice to ensure that people with HGG receive the support they need.

Exploratory Multi-Methods Evaluation of an Online Intervention for Carers of People with High Grade Glioma

Authors: Helen M Haydon, Alethea Blackler, Anna K Nowak, Danette Langbecker, Justin Collier, Georgia Halkett

Published: Neuro-Oncology Practice. 2023.

Link to full article: <https://doi.org/10.1093/nop/npad032>

What we found

Carers of people with brain tumour have a lot of needs. An online education and support program was developed to help carers with some of their needs. The online program was found to be helpful.

Important things we learned

Carers found the program helpful. They liked having information in one place. The program made them feel like they were doing well in their caring efforts and they weren't alone in their experiences and feelings. More experienced carers wanted more detailed information but thought the program would have been helpful to them at the beginning of their caring journey. Many of the carers suggested making the website more visually appealing and interactive.

Full summaries of these studies can be found on our website: www.btaa.org.au



NEED SUPPORT NOW?

PHONE 1800 857 221



To talk with experienced caregivers, call BTAA on the Support number: **1800 857 221**, and see the support groups available in your local area at www.btaa.org.au – look for support organisations.

Cancer Connect telephone (**13 11 20**)

Brain Tumour Patients Telephone Support Group Support Line **1300 755 632**
Monday - Friday 9am - 5pm
or email tsg@nswcc.org.au

Cancer Connections (online)
www.cancerconnections.com.au

Email btaa@shout.org.au

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