BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.
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AUSTRALIA'S VOICE FOR BRAIN TUMOUR SUPPORT AND ADVOCACY.

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BRAIN TUMOUR AWARENESS

INSIDE THIS EDITION

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The fight for government awareness and funding continues.

By Craig Cardinal

Significant inequity in government funding for brain tumour patients and families has again taken a blow for the Australian brain cancer community.

The Australian Brain Tumour Collaborative's (ABTC) 2025-2026 pre-budget submission was unsuccessful in obtaining $8.75m for 23 dedicated brain cancer coordinators to be incorporated into Australia's health system.

The on-going impact from lack of awareness and funding, confirms the need to press ahead with initiatives to ensure our community is appropriately funded and supported into the future.

Long term battle

- The brain cancer community has been lobbying government and formally requesting government funding for dedicated support brain tumour care coordinators and nurses since the early 2000's. Current brain cancer nurses and care coordinators across the country are funded by Not-For-Profit, philanthropic and state and territory-based health systems. The demand and complexity of the role require more nurse/care coordinators as a priority.
- The Australian Brain Cancer Mission, which was established in 2017 under Health Minister Greg Hunt, committed $50 million to Medical Research Future Fund over 10 years for brain cancer research with partner funding of $76.4 million Australian philanthropic and NFP community.

Despite this important commitment to research, $5 million per year of government funding is a long way short of what is required to make a significant impact.

Lack of awareness and funding. Why?

- Disease and Treatment: Brain cancer remains one of the most complex and challenging cancers to research with little to no real advancements in treatments and survivability for well over 30 years.
- Incidence and Burden: Government funding to cancer streams is broadly based on the incidence per 100,000 and number of deaths per year. When looking at brain cancer, the incidence rates place it in the 'less-common cancer' grouping. Subsequently, we are often labelled as a Rare Cancer and funding is assigned to that group.

However, the overall burden of disease from brain cancer significantly outstrips near all other cancers. The total cost burden to Australian society from IDH mutant low grade brain cancer in 2024 was $3.5 billion. This less common form of cancer also had over 12,000 Disability-Adjusted Life Years (DALY) during the same period.

The total burden of disease across brain cancers are not appropriately captured and government is subsequently not aware of the importance of dedicated funding.

Complex landscape: The Australian brain cancer support and research landscape is large and diverse. There are at least 10 national foundations involved in research and support. This is disproportionally high to all other cancers but is a consequence of the complexity and challenges associated with disease and treatments.

There is also a wide range of brain cancer support groups, nurses and care coordinators across the country seeking to support patients and families at the local level.

Obviously, this landscape is difficult for government to understand

No peak body: Whilst the large number of foundations and support entities are a positive, there is no singularly recognised national peak body for brain cancer. In reality, each of the national foundations provide critical research and/or support to the brain cancer community. But, for government, it is difficult to understand when looking at a single point for the ground truth of why and what are the pressing needs for our community.

The ABTC was formed to provide a united voice, however, the integral and vital part all the research and support stakeholders play needs to be understood by government.

Cost and support benefits realisation. The Mark Hughes Foundation recently funded important research that sort to understand the significant benefits (costs to government, providers, patients and families). The report was an initial look at the significant positive impact of dedicated brain cancer nurses/care coordinators.

This analysis needs to be adopted nationally to capture the holistic benefits to the health systems and patients.

The critical navigation and support work provided by the National Advocacy Service (NAS) has immense cost and patient benefits across health systems, government and patient and families. The NAS is funded by Cure Brain Cancer Foundation (CBCF) and operated and managed by the Peace of Mind Foundation (POMF).

The NAS is vital but as it relies on funding from CBCF, it is vital that government understands these benefits and seeks to support through funding.

There is very limited data on the current cost and support benefits – hence, government is unaware of what types and how much benefits are in place and need government support.

Nurse/Care Coordinator framework. As noted, the metrics around the benefits from dedicated brain cancer nurse/care coordinators needs to be captured. The Brain Cancer Rehabilitation Assessment Interventions for Survivorship Needs (BRAINS) program, funded through the ABCM and MRFF, is seeking to articulate a national model and framework for brain cancer care coordination.

Most government funded cancer streams have a fit for purpose national framework and model that provides optimise care for their respective communities.

The implementation of an agreed national model that supports brain cancer patients, families and care givers is essential to giving government and providers understanding and confidence in funding these models. As the BRAINS program develops the model, government awareness is pivotal to ensuring these frameworks are funded and supported.

Stepping forward with resolution

Understanding the problem set: The Australian brain cancer community has been very meaningfully and constantly engaged with government since the 2nd quarter 2023. This forthright engagement began when government departments changed policy that effectively removed brain cancer patients access to the National Disability Insurance Scheme (NDIS). The ABTC – with significant support from the NAS – painstakingly lobbied government over a 10-month period until the government and department understood the needs and the impact and subsequently overturned the policy decision.

In a similar vein, the ABTC have been engaging government and departments on the ACNNP and the inadvertent lack of acknowledgement and funding of the brain cancer community. As noted, the current broad-brush modelling does not reflect the true impact and burden and funding is assigned to groups such as rare cancer.

These decisions confirm government does not understand. The issues of lack of awareness and the reasons why identify why they don't understand, and the community needs to adjust to ensure we reset government's focus and commitment to our community.

Immediate actions

As a priority, BTAA will fund a commission an inaugural national Australian Brain Tumour Landscape - 2025 document. With support from the ABTC and all brain cancer support entities, the document will lay out the individual entities and how we contribute individually and collectively to improving the horrendous diagnosis of a brain tumour. The document will lay out the funding needs at a national and organisational level and ensure that we as a community are fully understood when government makes policy and funding decisions.

This is a high priority for our community. The document has been discussed and agreed amongst the ABTC as a turning point for our community. Ministerial engagement has confirmed that the document is important to shape their understand and will be well received.

General advocacy initiatives: In parallel, the ABTC are developing and progressing understanding of opportunities for other advocacy initiatives. Such as, consumers contacting their local members for support along with media campaigns and formal government engagements.

Summary

For many reasons, the plight of brain cancer patients and families has not been understood or adequately recognised. Recent engagement with government has been responsive to governments policy decisions in lieu of proper understanding. This responsive whack-a-mole approach to government engagement needs to reset. The government has confirmed – that, because of this forthright engagement – all stakeholders have a much better understanding of our need.

Our approach to the next steps is crucial to ensure awareness and funding is proportional to the very high need of our vulnerable conclusion. Despite the disappointments with governments recent decisions, our awareness of why - and governments awareness of our plight - have both drastically advanced. Our community will soon be recognised, and patients and families remain key to ensuring we finally receive the much needed support.

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 tumours 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.

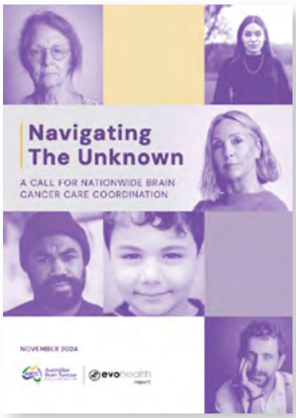
Our beautiful, sweet, shy but oh so cheeky 7 year old and our only child Ryley, was diagnosed with diffuse intrinsic pontine glioma (DIPG) in January 2022.
No treatment, no surgery, no cure! Go home and make memories was the only advice given!
We were told we have 6-12 months left - our baby beat the odds and had 14 months.
14 months of spoil, hold, kiss, touch and love him.
14 months to watch him slowly die, to lose every ability until he was completely bed bound, unable to speak, see, hear, eat and drink.....but this disease leaves them completely cognitive, He knew everything that happened to him as he lay trapped. This is DIPG.
Please support to help find treatment and cure into this most deadly childhood cancer.

Head to the Hill 2025 Builds on 2024 Success

The "Head to the Hill" event held at Australian Parliament House in November 2024 was a great success, drawing attention to the significant impact of brain tumours in Australia. The parliamentary courtyard was filled with over 2000 pairs of shoes, symbolising the devastating toll of brain tumours, while more than two hundred personal impact statements were displayed along the paths, representing the experiences of patients, families, and carers.

Attendees from across the country, including patients, families, and carers, came together to highlight the need for greater awareness, support, and research into brain cancer. Despite the busy parliamentary schedule, many politicians took the time to visit and show their support.

The event featured powerful speeches from key figures, including Craig Cardinal, Chair of the Brain Tumour Alliance Australia (BTAA) and leader of the Australian Brain Tumour Collaborative; Senator Catryna Bilyk; and Gail O'Brien of the Chris O'Brien Lifehouse. The speeches were followed by heartfelt stories from brain tumour patients, parents, and carers, underscoring the emotional and physical toll of the disease.



A major highlight of the event was the launch of the *Navigating the Unknown* report, commissioned by the Australian Brain Tumour Collaborative. This report highlights the unique and complex challenges faced by brain cancer patients and their carers. It calls for the establishment of Brain Cancer Care Coordinators (BCCCs) across Australia to help manage the difficult and often fragmented healthcare journey for brain tumour patients, especially in rural and regional areas where such services are scarce.

Craig Cardinal, in his speech, urged immediate action to increase the availability of BCCCs, noting that over 90% of these essential roles are currently concentrated in major cities on the east coast, leaving many patients in underserved areas without the crucial support they need. The Navigating the Unknown report outlines a clear plan for addressing these gaps in care and support. The report is an important new document, and defines a clearly articulated future direction, and I would encourage all members of the brain tumour community to study it.

The full report is available here.

It is clear that the Head to the Hill event has become one of the most significant for members of the Australian brain tumour community. Many see it as an opportunity to celebrate and commemorate the lives of loved ones that have been lost. Others, still undertaking the difficult brain tumour journey, seek awareness of their plight. All want to raise the awareness of the terrible toll of brain tumours, and the need for specialised care and more research.

A large event like this required a great deal of planning and hard work behind the scenes. The success of the event was made possible through the tireless efforts of the BTAA committee members across Australia. A special mention must go to Diane Dunn. Despite being a brain tumour patient herself, and currently undergoing treatment, Diane played a pivotal role in organising the event, demonstrating incredible vision, drive, organisation, dedication and leadership.

Planning for the 2025 event is now underway, although a final date is yet to be established, as parliamentary sitting dates and the Australian Parliament House event calendar, will not be clear until after the results of the May election.

Please make sure that you are registered as a subscriber on the BTAA website to receive regular updates about when this important event will be held. The BTAA monthly e-news will have all details as they come to hand each month.

Head to the Hill 2024, Australian Parliament House

To the woman sleeping in an MRI machine: listen, I love you, joy is coming

By Kate Bown

On Monday I fell asleep in an MRI machine.

It was early, before breakfast and the packing of the school lunchboxes and the raising of voices to get my children out the door and into the day. Perhaps I was soothed by the banging of those huge magnets. Or tired, that constant condition of young motherhood. I like to think I was dreamy and serene, a sleeping beauty in a glass coffin. It's only taken eleven-and-a-half years of brain scans not to worry and leak tears from my eyes that my life was in danger.

It was meant to be a surprise. My husband had booked the scan, hoping it would mean I would sleep well the night before and not lose my mind to uncertainty. But I had pressed him for details a few days prior and he had told me the plan.

Now on the morning of my scan, I am lying awake in bed, the sky outside my window as black and heavy as my heart. I decide to get up, make a cup of tea, and write in my notebook. I am not worrying. I am not scared that my brain tumour may one day obliterate me. I am tumbling, weary with the weight of all the things that I love. How could I ever let go?

And as I spin it is the small things that catch me — my old cat chasing her tail in the hallway, a game she has played since she was a kitten. A purple helium balloon resting on the ceiling, brought home from a music concert by my youngest daughter, its string tail brushing my shoulder. The twittering of birds outside the kitchen window, announcing the day. The sun rising over the river and behind the hills, washing the sky with the first morning colours. And on the bench, my late mother-in-law's orchid with stems of the loveliest pink flowers.

There is joy blossoming everywhere, I only have to look.

An MRI machine looks inside bodies, through skin and fat, under bones, to muscles and organs, nerve pathways and blood vessels. It uses powerful magnets, radio waves and a computer to make pictures of the things that hide deep within us.

The machine waits in the middle of the room, idling in its white and circular bulk — a lunar module, a portal to another world. In its centre is a tunnel, just the right size for a body. Smooth and cylindrical. When it is switched on, it becomes a magnetic monster. Hungry for metal.

I lie here on a padded stretcher, my socked feet hanging out of a cotton blanket. In the palm of my right hand, resting on my chest, is a buzzer. Snug over my head is a plastic cage. There is a small mirror angled so that I can see the radiographer going about their work. It is not uncomfortable. But it takes all my strength to be still in this tight white space.

Anyone who has been inside an MRI machine will know what it feels to be held in a state of unknowing terror.

You must not move but your heart is thumping against your ribs so hard you just might break. And here in this scanner, you know that love is a dangerous thing. For this machine can see what stalks through your body unnoticed. It knows you are a mortal thing.

There are foam buds in my ears and headphones over the top playing a classical radio station. Not that I can hear the music. The noise of the MRI machine is seismic. Not unlike a heavy-metal song — first the thrumming as the band warms up, then the lyrics, a loop of bangs and knocks, and the high-pitched whirring and buzzing, the bridge. You could learn to tolerate it. Many do not.

And to this machine's song I fall asleep.

All this time my husband waits, standing by the door of the MRI room. How hard this must be. To be on the outside. Steadying your fragile heart, knowing it will break if what you love is gone.

At home, our four children are waking up in their beds. The street is murmuring with birds. Bread is being unloaded from a truck parked on the curb opposite our house and is carried into the corner shop in brown plastic trays. Everyone and everything is beginning their day.

I am moving, sliding out of the centre of the machine. I come to a rest and the radiographer appears. Their hands reaching out to remove my helmet, take my ear buds, brush my shoulder. *How are you feeling?*, they ask.

I dress in a cubicle with a blue curtain. Put my watch back on. Untie my hair, so it falls just below my shoulders.

On the drive home from the hospital, my phone rings. It is my youngest son. I listen with my head leaning on the glass of the passenger window. *Mum, where are you?*, he asks in his slow big-boy voice, *When are you coming home?*

I tell him we are almost on our street. *We had an appointment, we will be home soon. Have you had breakfast?*

No, I am waiting for you, he says. Then quiet, just the sound of his breathing. But as we pull into the driveway, I hear his voice again, just above a whisper, *I love you, Mum.*

And his words are all the joy that I need to open the car door and step into the day.

COVER STORY

From Canberra to the Nation: How the ABCF is Redefining Brain Cancer Care

By Cathy Zhang

What if every brain cancer patient had the best support from day one — and a diagnosis came not justwith fear, but with hope?

The Australian Brain Cancer Foundation (ABCF) is working to make that a reality. Founded by Milena Skepev in the nation's capital, the entirely volunteer-run organisation ensures every dollar goes directly to patient care, research, and medical equipment.

Alongside Milena stands the ABCF Board and its Strategic and Medical Advisory Committees — a multidisciplinary group of experts covering every facet of brain cancer — from neurosurgery and oncology to palliative care, clinical nursing, research, and strategy — as well as law, accounting, and governance. Together, they form a collective committed to improving outcomes in brain cancer by supporting families, enhancing access to equipment, and investing in targeted research.

From day one, ABCF has been entirely volunteer-led — built on lived experience, determination, and a shared mission. The team has worked tirelessly to secure sponsorship for all operational costs, so that 100% of public donations go directly to programs. It's a model they've fought hard to build — and are committed to protecting — to ensure every dollar supports the care, research, and innovation the community deserves.

At the heart of ABCF's work are three core initiatives that form a wraparound model for brain cancer care:

- **Patient & Family Care:** A holistic, whole-family approach to support and navigation.
- **Research:** Driving breakthroughs through ANU partnerships — attracting and retaining brilliant minds.
- **Medical Equipment:** Providing advanced tools to improve outcomes and keep families close to home.

As neurosurgeon Dr Hari Bandi from Canberra Hospital notes, "What Milena and the ABCF team have achieved alongside the MAC in just 18 months is nothing short of remarkable. ABCF has created real, tangible hope—notjust for patients, but for us too."

ABCF CEO Milena Skepev and the ABCF Medical Advisory Committee Professor Leonie Quinn, Dr Hari Bandi, Dr Ganes Pranavan, A/Prof Peter Mews, Naomi Mitchell, Dr Kylie Jung, Dr Sivaraj Rajadorai

Canberra Brain Cancer Support Team

In March 2025, ABCF launched the Canberra Brain Cancer Support Team (BCST), delivered in partnership with Peace of Mind Foundation (POMF). This initiative connects patients and families to a dedicated Community Brain Cancer Navigator — providing emotional, practical and in-home support throughout the cancer journey.

Developed through extensive community consultation, the BCST directly addresses gaps identified by those it serves. As Milena explains: "We didn't just design this in a boardroom. We asked the community, we spoke to experts, and we listened."

The BCST is made possible thanks to the commitment of 13 founding partners, whose combined financial backing of $585,000 ensures the program can continue to support families well into the future.

Elizabeth Blooms, Canberra Brain Cancer Support Team

"The BCST is a game-changer for brain cancer patients in the ACT. It's the first time we've had a program offering dedicated, in-home support tailored to their needs," said Dr Hari Bandi, Neurosurgeon at Canberra Hospital. "This kind of wraparound care should be the standard — not the exception."

From left: Sam Allison, who raised over $9,500 for ABCF through marathon fundraising; Sofia Milicevic and Claudia Cataldo who also ran to raise vital funds.Their efforts supported ABCF's Biobanking program - thank you for turning kilometres into impact.

> "**100%** of all donations, go directly towards our initiatives."

DONATE

Canberra Brain Cancer Monthly Family Support Group
Recognising that brain cancer impacts entire households, ABCF is also launching the Canberra Brain Cancer Family Support Group Network in July. Co-hosted in collaboration with Brain Tumour Alliance Australia (BTAA), the group is built on lived experience and structured to be inclusive, accessible and nurturing.

Held monthly at the Griffith Neighbourhood Centre, each session includes:

- Peer-led support rooms run by BTAA, with a professional counsellor on hand to guide tougher conversations
- Family-friendly activities and child-inclusive spaces
- A welcoming environment to share life's highs and lows, with cultural and multilingual support
- Transport assistance to ensure no one misses out

"We're not here to duplicate services. We're here to fill the gaps — with compassion, strategic collaboration, and expert leadership." — Milena Skepev

ACT Brain Cancer Biobank
ABCF also addresses critical gaps in brain cancer biobanking. After seed funding from ACT Health ended in February 2025, the ACT Brain Cancer Biobank faced shutdown. ABCF swiftly intervened with a $37,500 emergency donation to preserve invaluable patient tissue samples.

Milena explains, "It's about honouring what patients and families have already given. Every sample is a story, a contribution—and for many, a final gift. We must ensure those gifts aren't wasted."

While ABCF's emergency donation secured the immediate future of the Biobank, long-term funding remains critical. The Foundation is now seeking 50 Founding Partners to pledge $15,000 annually—funding the full pipeline from tissue collection and sequencing to organoid creation and drug testing.

"What we learn from each sample could unlock better treatment for the next patient. Sustaining the Biobank means we're not just storing tissue — we're preserving opportunity," said Professor Leonie Quinn, Group Leader at ANU and Head of the ACT Brain Cancer Biobank research team. "Biobanking plays a vital role in preserving patient tissue and advancing personalised medicine."

Collaboration
ABCF's impact is powered by collaboration — not only with leading institutions like ANU and the Canberra Hospital, but also with like-minded brain cancer charities including BTAA and POMF. These partnerships extend the Foundation's reach and deepen its impact across research, care, and community support.

Though Canberra-born, ABCF's vision is national — but that journey begins at home. Only after caring for the Canberra community and refining its model will ABCF look to scale it across the country. By piloting care programs that are locally tested and proven, the Foundation aims to transform brain cancer support nationwide — ensuring no patient faces this disease alone. Every step is guided by frontline expertise, grounded in real-world needs, and focused on what matters most now. And as ABCF expands into new regions, funds raised in those communities will stay local — supporting patients and families where the need exists.

Whether you're a patient, carer, fundraiser or clinician — there's a way to get involved. Access support, share your voice, or donate at www.abcf.org.au.

Register for ABCF programs

Marko, a Year 6 student, with Professor Leonie Quinn. He raised over $3,500 for ABCF's Biobank program at ANU in honour of his grandmother, who is living with brain cancer. Thank you, Marko, for your drive and commitment to change.

Peace of Mind Foundation Expands Community Days to Reach More Families in 2025

Peace of Mind Foundation, one of Australia's leading brain cancer support charities, is dedicated to providing care, connection, and hope to those affected by brain cancer. Supporting over 1,000 families each year, the foundation plays a crucial role in ensuring patients and their loved ones receive emotional, practical, and social support during their journey.

In 2025, Peace of Mind Foundation is expanding its impactful Community Day initiative, reaching even more families across the country. Community Days are designed to offer patients, carers and loved ones the opportunity to come together for a day to form meaningful friendships, create new experiences, and make lasting memories in a supportive and encouraging environment. These events provide a much-needed break from the daily challenges of a brain cancer diagnosis, offering moments of joy and connection in a time of great difficulty.

This year, the foundation is bringing Community Days to a new location and returning to Adelaide, ensuring that more families can benefit from these uplifting experiences. The first Community Day will take place in Western Australia on Saturday, 31 May, at Perth Zoo, from 10 am to 4 pm. Thanks to the generous support of Rewilding Minds, this special day will bring together patients, carers, and families for a day filled with laughter, companionship, and unforgettable wildlife encounters. Registrations will shortly be open via Peace of Mind Foundation's website.

Following the successful inaugural event in 2024, Peace of Mind Foundation will return once again to South Australia, with a Community Day scheduled for September 2025 (exact date to be advised). This event, made possible through the generous support of the NeuroSurgical Foundation (NRF), will provide another opportunity for families to step away from the pressures of treatment and enjoy a day of relaxation and support.

Community Days are more than just social gatherings—they are an essential part of the foundation's mission to bring connection, courage, and community to those facing the harsh realities of brain cancer. By creating a space where carers and loved ones can bond with others who understand their journey, these events help to build a network of support that lasts beyond the day itself.

Peace of Mind Foundation believes that no family should face brain cancer alone. Through initiatives like Community Days, the charity continues to bring hope, resilience, and solidarity to those who need it most. With the generous support of partners like Rewilding Minds and NRF, 2025 promises to be a year of greater reach, stronger connections, and unforgettable moments for families impacted by brain cancer.

To learn more about Peace of Mind Foundation, upcoming Community Days, and how you can get involved, visit www.peaceofmindfoundation.org.au.

peace of mind foundation

One Size Prognosis May Not Fit All

By Anne Markiewicz

My name is Anne and I was diagnosed with a GBM 2.5 years ago. At that time I was told I had 12-18 months to live and that only 5% survive longer than 5 years. I immediately responded that I could be part of the 5% group, and that I would strive for that outcome. I was determined to be an outlier.

Despite my resolve, I found the dire prognosis together with treatment effects, led me to a state I had never been in before, somewhere between deflated and depressed. I sought counselling to ameliorate my rising depression. This was a very dark period for me, as I wrestled with an internal struggle between accepting the grim prognosis and developing and strengthening my resolve to overcome the odds. I experienced battles between two contradictory voices in my head drawn from my childhood. One voice said: “Hold an optimistic attitude to life, and, when faced with a challenging situation there is always a workaround or an alternative” and the second voice responded: “Doctors are the experts who know what they are doing and they are always right”.

The first 12 months were a difficult period for me, as the voices in my head wrestled with each other. As time went on and I passed the 12 month timeframe, I became more certain that the prognosis given to me was not a final determination and that it may not apply to me at all.

I located a website where many members are long term GBM survivors. I had found evidence at last, that it is possible to outlive the grim 12-18 months prognosis. This same timeframe had been given to many of the long-term survivor members of this website regardless of which country they had lived in. It seemed to be a universal practice. To add icing to the cake of discovering a group of long-term survivors on a website, I also came across a lecture given by Dr. Henry Friedman, a leading neuro-oncologist at Duke Cancer Centre, who concluded from his contact with long-term survivors, that it is a myth often fuelled by internet searches that GBM is incurable and that it is not incurable for everyone.

As a researcher who worked extensively with datasets and data analysis, I also came to realise that the dataset used for determining for GBM survival is flawed. This is because it is based on dated retrospective data that has not been disaggregated for important variables such as location; degree of operability and excision; age and overall health status. I thus formed the view that the one size fits all prognosis allocated to each person with GBM may in fact do more harm than good. It certainly had that effect on me as I struggled to assimilate the prognosis and vacillated between optimism and despair.

Having lost faith in the robustness of the prognostic dataset for GBM I reassessed my future prospects and re-engaged with the world. I recharged and boosted my optimism and re-commenced activities and travel that I had believed were no longer possible to enjoy again. I am now heading toward 3 years post-surgery, a milestone that I initially believed I could never achieve based on the prognosis derived from this dataset.

What I have learned from this experience is the dangers of handing out a prognosis that is based on a questionable dataset. This common practice can cause harm to the newly diagnosed by suggesting imminent death and destroying their opportunity and motivation to enjoy and fully participate in the immediate years ahead.

Of course, for some, the prognosis of 12-18 months may be accurate and will have allowed them time to plan for their personal affairs accordingly. The issue is rather than applying a one size fits all approach to a prognosis it would be fairer to provide a customised and individualised prognosis that is based on unique factors to that individual’s circumstance and is thus likely to have a higher degree of accuracy.

If asked what my recommendations would be, the first would be to update the dataset for GBM survival based on contemporary data. The second would be to disaggregate that dataset for factors such as country, location, degree of operability, type of surgery, pre-existing health status, age, gender and genetic characteristics of the tumour, among other salient factors. The third would be to train medical specialists to be more circumspect when giving out a prognosis and to explain the bell curve, means there can and will be outliers to that prognosis. The next suggestion is for those diagnosed with GBM to believe that they can and will become an outlier, as optimism can only act to build immunity, avert depression and ensure that the person lives their life to achieve maximum fulfillment. The final recommendation is for medical specialists to always seek informed consent from their patient prior to handing out a prognosis. Some may prefer not to know and live in the moment.

BTAA Embarks on Organisational Renewal to Strengthen National Impact

The Brain Tumour Alliance Australia (BTAA), one of the nation's longest-standing brain tumour support organisations, is embarking on a revitalisation of its operating model to ensure it remains responsive, effective, and fit for purpose. While BTAA continues to uphold the core principles that have shaped its foundation, the committee has recognised the need to adapt to the evolving needs of the brain tumour community.

To support this transformation, BTAA has identified the need for a dedicated, independent professional resource to help strengthen its organisational posture. This initiative aligns with BTAA's commitment to working collaboratively with all brain tumour support, research, and advocacy stakeholders to ensure the delivery of high-quality, community-driven services.

BTAA committee member Philip Dunn has led a focused recruitment campaign to secure a candidate capable of working alongside the committee and broader national organisations to set out a clear roadmap for BTAA's future direction. The process was highly competitive, with many qualified applicants. After careful consideration, the committee is pleased to announce the appointment of Trevor Stuart as a consultant to BTAA.

Trevor brings with him a wealth of relevant experience in organisational development and business process analysis, and will commence a six-month engagement with BTAA in late April. His initial focus will be a comprehensive review of BTAA's organisational structure, operational effectiveness, and its visibility and positioning within the brain tumour community.

A detailed and ambitious scope of works has been outlined for Trevor, which includes evaluating BTAA's internal systems and external engagement mechanisms to ensure they effectively represent the interests and needs of those affected by brain tumours across Australia.

The BTAA committee will work closely with Trevor throughout this process to ensure a collaborative and transparent approach, particularly in strengthening partnerships with key stakeholders. As his work progresses, BTAA will share updates and insights from Trevor's findings, including reflections on the state of the brain tumour community and recommendations for BTAA's future.

This is an important step in ensuring BTAA continues to evolve as a strong, independent voice for all Australians impacted by brain tumours.

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Trevor Stuart joins BTAA to support our future planning and growth.

I Don’t Know

By Jane Whitehead

Death

When will I die? *How will I die?* What happens after I die....

Wait.

I will address Death in its rightful place - at the end of this unfortunate, but true story.

Let me start at the beginning.

Diagnosis. Astrocytoma, IDH-mutant, WHO grade 4. Removed from my brain on August 4, 2023. According to AI-generated info, this tumour is aggressive and fast-growing, formerly classified as a glioblastoma (GBM). Symptoms include headaches, speech issues, vision problems, cognitive decline, and seizures. Treatments include surgery, radiation, and chemotherapy. Average survival: 12–18 months. Only 25% live longer than a year.

Prognosis. 24 months to live. That’s what I was told. My brilliant surgeon removed 95% of the tumour. Then she said, “You will die from this. Do your bucket list.” I appreciated her honesty, but how could she know? She hadn’t studied my tumour in my body. Science changes all the time—my tumour type was reclassified just recently. Prognosis is based on population studies, not individual cases. If classification can change, what else might they be wrong about?

It’s comically arbitrary at times, these reclassifications and statistical predictions. One moment you’re the recipient of a death sentence, the next you’re slightly more “optimistic” because someone in a lab decided your tumour belongs to a new category. I couldn’t help but wonder—maybe in a few years they’ll reclassify it again. Maybe I won’t die at all from this.

You Will Die From This. Should I undergo the eight-month standard-of-care treatment? My oncologists spoke of “good results” for my tumour type. My surgeon was more blunt. If I’m dying anyway, what’s the point?

Treatment meant six weeks of daily brain radiation (excluding weekends and public holidays), plus daily chemotherapy pills (temozolomide). Then four weeks of rest. Then six months of higher-dose chemo.

Side effects? Nausea, constipation, chemo rash, extreme fatigue, toxicity that clings to everything. Temozolomide is so potent, you’re told to flush the toilet with the lid down and wash clothes separately. Everyone responds differently, and some don’t make it through.

It’s a cruel irony that the treatment designed to extend your life can feel like it’s killing you. You’re torn between wanting to live and wondering if surviving treatment is worth it. No one can answer that but the person going through it.

Decision. I chose treatment. Not because I believed in it wholeheartedly. Two reasons:

1. I’m intimidated by experts. Who am I to question oncologists? They’re smart. They save lives. I quit biology in Year 9.
2. I couldn’t absorb the information they gave me while I was stressed. Diagrams, acronyms, percentages—it all blurred together. I nodded along, trying to look like I understood.

They meant well. They took the time to explain everything, even drawing little flowcharts and diagrams—this gene leads to that protein, this mutation responds better to this drug, here’s a pie chart, here’s a bar graph. But anxiety is a thick fog. Nothing got through. I nodded and agreed because it was easier. I didn’t want to appear ungrateful or uncooperative.

I was a good girl. I said yes to standard-of-care.

Treatment. Radiation. Chemotherapy. Then rest. Then more chemo. I made it through, though not unscathed. Radiation burned my forehead. My hair fell out, especially on the right, where the tumour was. I vomited, scratched at rashes, and watched my blood cell counts drop. I felt like I’d been poisoned.

To get through treatment, I took an anti-nausea pill an hour before chemo. I had to. Without it, the pills wouldn’t stay down. Toward the end, I developed a widespread, itchy chemo rash. I had a low white blood cell count and lived in fear of infection.

There were days I couldn’t get out of bed. Days I looked in the mirror and didn’t recognise myself. The fatigue was bone-deep. The fear was ever-present. I was afraid of dying, yes—but more than that, I was afraid of dying without having lived.

The emotional toll? Too raw to write about in detail. The dread. The fear. The depression. It was all-consuming. Was it worth it?

I don’t know.

READ THE FULL ARTICLE ON OUR WEBSITE

www.btaa.org.au/news/stories

Time to Transform Childhood Brain Cancer Research

Mark Hughes Foundation

At MHF, we are deeply committed to advancing brain cancer research, which is why we are thrilled to announce our significant contribution of $500,000 toward the Australian Government's $20 million funding initiative. This contribution will support Australian researchers in their efforts to revolutionise the treatment landscape for childhood brain cancers, offering new hope for Australian children, adolescents, and young adults battling these devastating conditions.

MHF Research Centre Stream Leader Professor Matt Dun has been awarded a $2 million National Health and Medical Research Council (NHMRC) grant to help progress its mission to develop breakthrough treatments for the most lethal form of childhood cancer, Diffuse Midline Glioma (DMG). With the Mark Hughes Foundation providing an additional $200,000, Professor Dun described the $2 million NHMRC MRFF grant as a crucial step toward tackling the most devastating disease.

We are also extremely proud to contribute $300,000 as part of the TarGeT Collaborative—a groundbreaking partnership that aims to fund essential clinical trials for targeted treatments in children and young adults diagnosed with high-grade gliomas, including Diffuse Intrinsic Pontine Glioma (DIPG).


INTRODUCING THE

TARGET COLLABORATIVE

Supporting ANZCHOG Funding Targeted Paediatric High Grade Glioma Therapy Clinial Trials

Together, these initiatives are driving hope and progress in the fight against paediatric brain cancer.

Full Story on TarGeT Collaborative HERE.

PATIENT INFORMATION & SUPPORT SESSIONS

The Brain Cancer Group

BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.
1800 857 221

A TBCG and BTAA partnership.

The Brain Cancer Group (TBCG) is proud to have partnered with Brain Tumour Alliance Australia (BTAA) to run Patient Information and Support events this year. These will be held in person on the North Shore Medical Campus.

To help us gauge interest and plan, we would like to hear from you.

Scan QR code to fill in the 1 minute survey

Click here to fill in the 1 minute survey

The Brain Cancer Group

8th Annual Awareness Raising Event at NSW Parliament House

events.humanitix.com/tbcg-parliamenthouse2025

FREE EVENT - SAVE THE DATE

27 MAY 2025
5:45pm - 8:00pm

Hilton Sydney
488 George Street

Parliamentary host

The Hon. Sophie Cotsis, MP

Theme
Bridging the Gap:
Advancing Brain Cancer Care in Regional NSW

Attendees will include TBCG brain cancer specialists, researchers, ambassadors, patients, carers and major donors.

SCAN QR CODE
TO VIEW PROGRAM
& RSVP FOR THIS EVENT

NEED SUPPORT NOW?

PHONE 1800 857 221

BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.

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

SPREAD THE WORD!

Please LIKE, ADD, SHARE, COMMENT and SPREAD the word via our Twitter, Facebook and LinkedIn accounts! This not only helps our voice to be heard but also gives you a chance to reach out, interact and communicate with BTAA and the wider brain tumour community!

1800 857 221
www.btaa.org.au

Brain Tumour Alliance Australia

@BrainTumourAA

Search 'BTAA' on YouTube

BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.
1800 857 221

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