The Australian Brain Cancer Landscape 2025

BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.
1800 857 221

Revealing the burden and economic cost of brain cancer to Australia

October 2025

Supported by

Australian Brain Tumour Collaborative

Endorsement

The Australian Brain Cancer Landscape has been developed by Brain Tumour Alliance Australia (BTAA) with support from the Australian Brain Tumour Collaborative (ABTC).

ABTC Australian Brain Tumour COLLABORATIVE

Cure Brain Cancer Foundation

peace of mind foundation

COGNO COOPERATIVE TRIALS GROUP FOR NEURO-ONCOLOGY

MHF MARK HUGHES FOUNDATION

PoCoG Psycho-oncology Co-operative Research Group

the brain cancer centre MANY MINDS. ONE FOCUS. | Founded by Carrie's Beanies 4 Brain Cancer

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The Brain Cancer Group

Developed by Biointelect

Biointelect

Level 4, 143 Macquarie Street,
Sydney NSW
Australia 2000

T 1300 800 984
E requests@biointelect.com
www.biointelect.com

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Abbreviation list

ABCARA	Australian Brain Cancer Research Alliance
ABCM	Australian Brain Cancer Mission
ABTC	Australian Brain Tumour Collaborative
ACNNP	Australian Cancer Nursing and Navigation Program
AFTD	Assessing Fitness to Drive
ANZCHOG	Australian and New Zealand Children’s Haematology/Oncology Group
BCCC	Brain Cancer Care Coordinator
BRAINS	Brain cancer Rehabilitation, Assessment, Intervention of survivor NeedS
BTAA	Brain Tumour Alliance Australia
COGNO	Cooperative Trials Group for Neuro-oncology
DALYs	Disability-adjusted Life Years
ED	Emergency Department
GBM	Glioblastoma Multiforme
GP	General Practitioner
MBS	Medicare Benefits Scheme
MDT	Multidisciplinary Team
MRFF	Medical Research Future Fund
MRI	Magnetic Resonance Imaging
MSAC	Medical Services Advisory Committee
NAS	National Advocacy Service
NCI	National Cancer Institute
NDIS	National Disability Insurance Scheme
NHS	National Health Service
PBS	Pharmaceutical Benefits Scheme
TGA	Therapeutic Goods Administration
UK	United Kingdom
US	United States
WEHI	Walter and Eliza Hall Institute
WHO	World Health Organization

All amounts in this paper are expressed in Australian Dollars unless otherwise indicated.

Foreword

Professor Richard Scolyer AO

BMedSci, MBBS, MD, FRCPA, FRCPath(UK), FAHMS

Senior Staff Specialist, Tissue Pathology & Diagnostic Oncology, Royal Prince Alfred Hospital; Conjoined Professor, Faculty of Medicine and Health, The University of Sydney; Member, Melanoma Institute Australia; 2024 Australian of the Year

Brain cancer is one of the most complex and lethal forms of cancer, and it has remained one of the least understood. Despite the advances we have seen in many other cancer types, brain cancer survival rates have improved only marginally over decades. To help address these issues, the Australian Brain Cancer Mission has made significant progress by accelerating research, clinical trials, and collaborative science. However, we must continue to amplify these efforts to improve survival rates and quality of life issues.

The Australian Brain Cancer Landscape 2025 is a vital step in uniting Australia's brain cancer research, clinical, and patient support communities. This document provides the government, funders, and the broader community with a clear, coordinated understanding of who is working in the field, what has been achieved, and, critically, what still needs to be done.

Our research priorities are ambitious but achievable: to increase survival, reduce the burden of treatment, and ultimately to discover treatments that are less toxic and preserve quality of life. That work must be supported by policy, funding, and recognition that brain cancer requires sustained coordinated national commitment.

This Landscape sets out that vision. I am proud to support it.

Professor Richard Scolyer AO

Foreword

Gail O’Brien AO

Board Director, Patient Advocate Chris O’Brien Lifehouse

As both a health professional and someone who has walked the harrowing path of personal loss, I am pleased to stand with The Australian Brain Tumour Collaborative which was created to bring together the many dedicated organisations, support groups, and researchers who share a common goal: to improve the lives of those affected by brain cancer.

It is now 19 years since my beloved husband Chris O’Brien, was diagnosed with a lethal brain tumour and given 4 to 6 months to live. He died 2 ½ years later in June 2009.

At the age of 54, he was a world-renowned cancer surgeon at the height of his career the diagnosis came as a hammer blow.

Caring for a loved one with brain cancer is a profoundly isolating and soul-crushing experience—a truth I have lived both personally and professionally.

Prof Chris O’Brien AO
1952 - 2009

The unique plight that brain cancer patients find themselves in, calls for a precise and relentless commitment, including patient navigators and care coordinators, to address their deeply personal needs.

With just 1,500 to 2,000 new diagnoses each year in Australia, it is a rarity. That is no debate. but it feels that it serves as an excuse for negligible government support—a cruel calculus that ignores the sheer devastation wrought on patients’ independence, dignity, and families and leaves countless patients and their families grappling in silence.

The profound impact of brain cancer is no less deserving of focused attention as other cancers. It’s devastating nature demands specialized care models and targeted resources.

My husband’s words from 19 years ago stay with me today, *“If it’s this hard for us, how is it for everyone else?”*

This document – The Australian Brain Tumour Landscape – 2025 – is more than a report. It is a roadmap for how we can, and must, do better. It recognises the essential roles of both scientific discovery and compassionate, comprehensive support. It makes clear the urgent need for government recognition, funding, and policy that reflect the unique challenges faced by brain tumour patients.

As a collaborative group with a unity of purpose, we must be successful in making a positive difference in the future, to all those whose lives are upended by this relentless disease.

Gail O’Brien AO

Executive summary

Revealing the burden and economic cost of brain cancer to Australia

The Australian Brain Cancer Landscape has been developed by Brain Tumour Alliance Australia (BTAA) with support from the Australian Brain Tumour Collaborative (ABTC), to provide government, policy makers and the community with a clear, evidence-based understanding of brain cancer, one of the most devastating and complex diseases affecting Australians.

The Australian Brain Cancer Landscape seeks to:

- Present the wide-ranging burden brain cancer places on patients, families, care givers, health systems, and society as a whole
- Unite the voice of the national brain cancer community and present a clear pathway for coordinated, sustained action
- Reset government understanding and response, ensuring brain cancer is recognised as a national priority
- Call for equitable funding and support from government, delivered through co-designed and co-funded partnerships that reflect brain cancer's true burden, not just its incidence

The need for action: A devastating disease with an outsized burden

Brain cancer stands as one of the most complex and devastating diseases facing Australians today, impacting not just those diagnosed, but their families, carers and the broader community. Its aggressive nature and unpredictable progression cause profound physical, cognitive, and emotional suffering, often robbing individuals of their independence, dignity, and future aspirations. The journey for patients is marked by overwhelming challenges - frequent hospitalisations, invasive treatments, and the uncertainty of recurrence that has a heavy psychological impact.

Despite these realities, brain cancer remains largely overlooked in terms of funding and research priorities, with survival rates stagnating over the past three decades. The burden extends well beyond the medical aspects, as families and carers grapple with financial strain, disrupted livelihoods, and the emotional weight of supporting loved ones through relentless adversity.

Low survival outcomes and a devastating disease burden

Although brain cancer is classified as a less common cancer based on incidence, it imposes one of the highest total burdens of any cancer.

Brain cancer kills more Australians under 40 years of age than any other cancer and is the leading cause of cancer-related deaths in children and young adults, causing among the highest years of life lost per diagnosis. By 2050, more than 23,000 Australians are expected to be living with brain cancer, with approximately 2,650 deaths annually.

By 2050,

23,352
Australians are expected to be living with brain cancer

2,650
Australians are expected to die each year with brain cancer

3,200
Australians are expected to be diagnosed with brain cancer per year

Source: Biointelect analysis [1]

Despite its severity, five-year survival rates have remained largely unchanged over the past three decades, improving only marginally from 19% to 23% between 1990-1994 and 2015-2019. This stagnation highlights the urgent need for renewed investment and strategic focus.

Over the last three decades, brain cancer has seen one of the **lowest improvements in 5-year survival rate (~4%)** across all major cancer types

Source: Australian Institute of Health and Welfare [2]

An outsized economic and social impact

The economic and social costs to patients, families, carers, the health system and society far exceed those of more common cancers.

In 2025 alone, brain cancers are projected to result in 38,536 years of life lost due to premature death, with an additional 4,249 years lost to disability, totalling 42,794 disability-adjusted life years (DALYs).

In 2025 alone, brain cancers are projected to result in:

38,500

years of lost life due to premature death (averaging 22.7 years per patient)

4,250

years of healthy life lost due to disability

42,750

disability-adjusted life years (DALYs) of healthy life lost due to disability

Source: Biointelect analysis [1]

The predicted loss of productivity due to diagnosis is estimated at $251.3 million, with a further $153.1 million lost due to caregiving responsibilities. Informal care is estimated to require 3.7 million hours in 2025 in Australia. Biointelect analysis estimates the total societal cost at $0.85 billion in 2025, rising to $3.2 billion by 2050 if current trends continue.

Total societal cost of brain cancer estimated to be **$3.2 billion** by 2050

Source: Biointelect analysis [1]

Healthcare-related costs are similarly significant, with estimated national expenditure of $313 million in 2025, equating to $29,963 per affected individual. These figures reflect the high treatment burden and systemic inefficiencies that contribute to late-stage diagnoses and ongoing financial strain on Commonwealth, State, and Territory health budgets.

Ongoing brain cancer treatment costs Commonwealth, State and Territory governments an estimated **$313 million** in 2025

Source: Biointelect analysis [1]

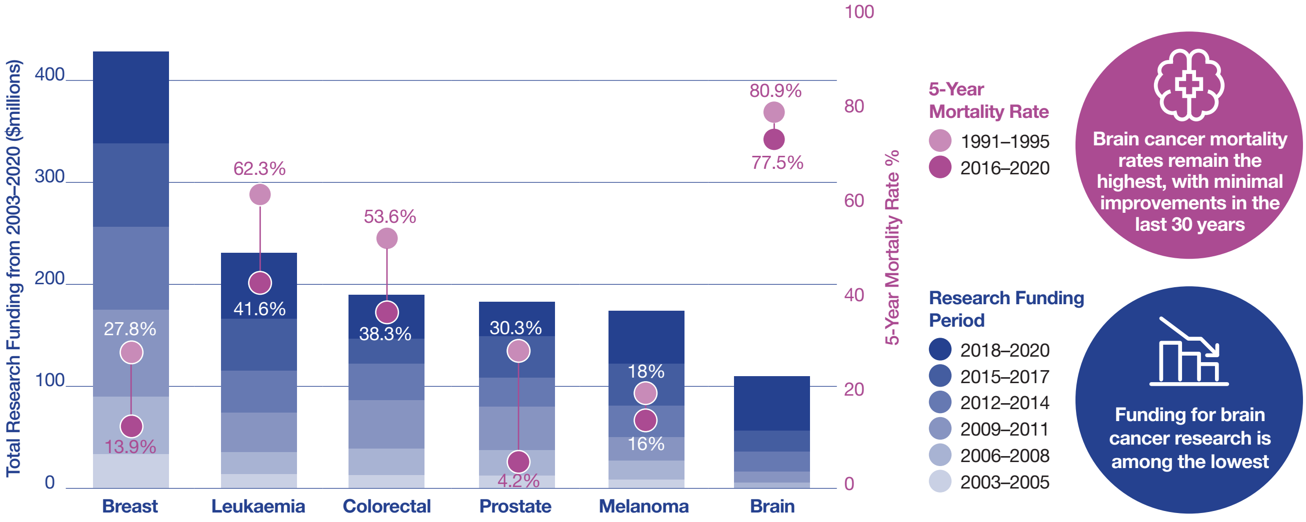
Funding disparities and survivorship costs

Considering the profound burdens from both the disease and its treatment and the number of deaths each year relative to incidence, brain cancer receives disproportionately low funding compared to other cancers.

Between 2003 and 2020, brain cancer research received only $111.6 million in government funding, far below breast cancer ($431.6 million), leukaemia ($234.7 million), colorectal cancer ($190.8 million), prostate cancer ($184.7 million), and melanoma ($175.5 million).

This disparity is further highlighted by survivorship studies showing that individuals with brain cancer incur the second highest mean annual healthcare expenditure per person at $30,264, almost double the average across all cancers at $15,889.

Figure 1: Long-term trends in cancer research funding compared to 5-year mortality rate in major cancer types



Brain cancer mortality rates remain the highest, with minimal improvements in the last 30 years

Funding for brain cancer research is among the lowest

Source: Cancer Australia (2023), Cancer Research in Australia: An overview of funding for cancer research projects and programs in Australia

A call to action: Co-designing a national strategy to improve brain cancer outcomes

Achieving better outcomes for Australians affected by brain cancer relies on three interconnected pillars:

Research & Trials + **Clinical Care** + **Support Services**

This Landscape document is organised around these pillars, each of which significantly shapes the experiences and outcomes for people with brain cancer. Each pillar has key achievements and opportunities, all tied to a specific ask of government. Advancing these pillars in unison is essential, as progress in one area both supports and depends on progress in the others.

BTAA, with the support of all signatory organisations, calls for government to commit to three priority actions.

Research & Trials: Invest $200 million over 10 years to establish the Australian Brain Cancer Mission (ABCM) 2.0

Establish ABCM 2.0 as a renewed strategic partnership

Reset and renew the ABCM as ABCM 2.0, a co-designed partnership between government and philanthropic stakeholders. To enable this, $200 million should be committed by government over a 10 year period. This would be strengthened by additional philanthropic contributions.

This initiative will formalise shared governance, align strategic priorities, and secure sustainable funding to accelerate national efforts in brain cancer research, treatment and survivorship.

Build a national research and trials roadmap

Develop a comprehensive National Brain Cancer Research and Trials Roadmap that spans the full research continuum:

- Basic discovery science
- Translational research
- Clinical trials
- Survivorship and supportive care

This roadmap will guide coordinated investment, foster collaboration, and ensure measurable outcomes across all stages of brain cancer research.

Strengthen research enabling capabilities

Invest in the development of the workforce, infrastructure, data systems and collaborative networks that are needed to deliver scientific and clinical breakthroughs.

Research and clinical trials create the knowledge, treatments and innovations that clinical and supportive care teams can implement.

Clinical Care: Invest $8.75 million to implement a national Brain Cancer Care Coordinator (BCCC) framework, including 23 specialised coordinators

National framework for coordinated care

Implement a national BCCC Framework, building upon the framework presented in this paper, to deliver consistent, end-to-end support for patients, from diagnosis through treatment, survivorship, recurrence and palliative care.

Embed coordinators in every care team

Embed BCCCs into multidisciplinary teams (MDTs) across metropolitan, regional and rural settings to ensure coordinated, equitable and patient-centred care nationwide.

Data driven deployment and outcomes

Leverage the BRAINS Program data to identify priority areas, direct resources to greatest need, and track measurable improvements in patient outcomes and service delivery.

Clinical care ensures every patient can access and benefit from best practice care and treatment, while reducing fragmentation and health system burden.

Support Services: Sustain and scale the National Advocacy Service (NAS) with $1.175 million in dedicated annual funding

Sustain and scale the NAS

Secure and expand the NAS, delivered by Peace of Mind Foundation and currently funded by Cure Brain Cancer Foundation, to ensure continued support and greater impact.

Invest in workforce capacity

Provide dedicated funding for 8 FTE staff ($1.175M per year) to deliver tailored navigation, psychosocial support, and ensure equitable national reach.

Formalise the NAS as a peak national service

Recognise the NAS as a national peak consumer support service, fully integrated with BCCCs and aligned with national cancer navigation programs.

Support services provide the scaffolding families need to survive the journey and ensures lived experience informs research and care design.

Brain cancer devastates lives, but change is possible.

By investing in Research & Trials, Clinical Care and Support Services as a unified national strategy, government can support the delivery of breakthroughs, equity and hope that Australians with brain cancer deserve.

Research & Trials: Invest $200 million over 10 years to establish the ABCM 2.0

Clinical Care: Invest $8.75 million to implement a national BCCC framework, including 23 specialised coordinators

Support Services: Sustain and scale the NAS with $1.175 million in dedicated annual funding

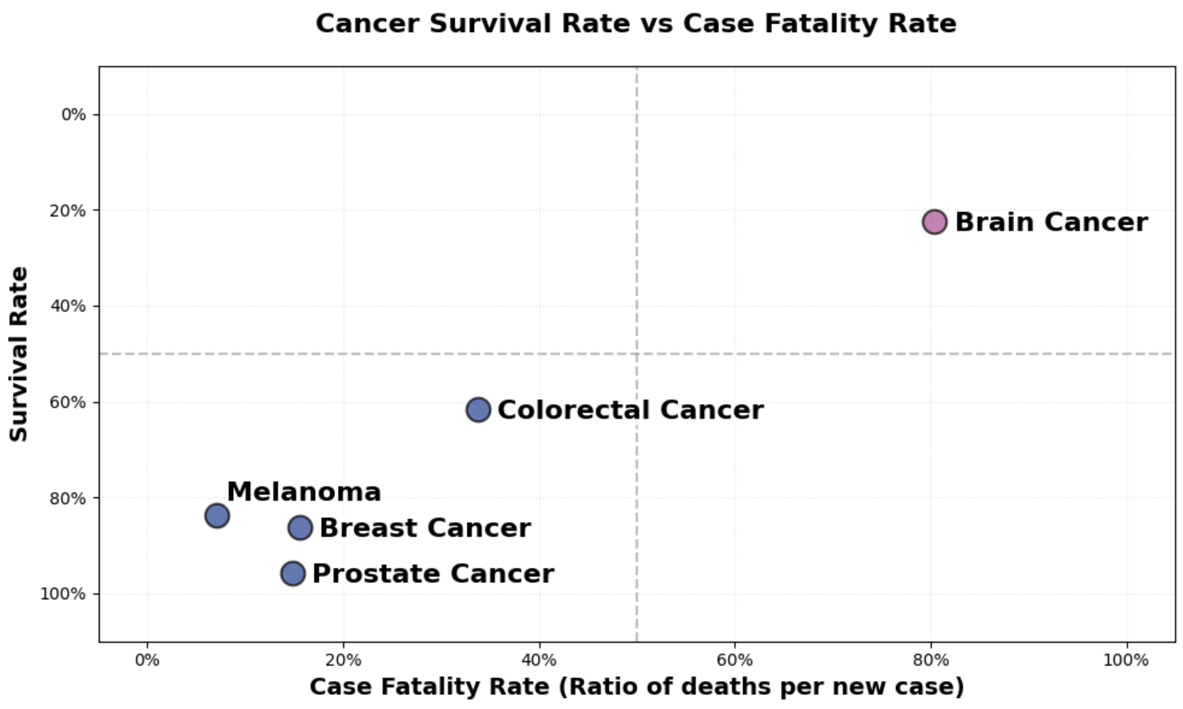
The urgent need to confront the burden of brain cancer

Brain cancer remains one of the most devastating cancers in Australia

Brain cancer is among the most complex and devastating diseases across all age groups, with over 100 distinct tumour types classified by the World Health Organization (WHO) [3]. These tumours vary significantly in their biological behaviour, treatment responsiveness, and prognosis, necessitating highly individualised care strategies [4].

In Australia, brain cancer remains one of the most devastating cancers, with around 1,924 Australians diagnosed and 1,579 lives lost in 2023 alone [5]. Despite advances across many other cancers, five-year survival for brain cancer is only about 23%, one of the lowest of all major cancers [6]. The burden extends far beyond the patient, with families often facing sudden and intensive caregiving responsibilities, significant financial strain from out-of-pocket costs, and loss of workforce participation [7]. For regional and remote patients, the need to travel for specialist care compounds inequities [8]. The economic impact is considerable, combining high hospital and treatment costs with lost productivity and the unmeasured toll on carers. Targeted investment through initiatives such as the ABCM is critical to improving survival, quality of life, and reducing the disproportionate social and economic burden borne by Australian households [9].

Figure 2: Case fatality rate compared with 5-year survival of major cancer types



Source: Australian Institute of Health and Welfare [2]

The clinical complexity of brain cancer subtypes

Tumours are graded from Grade I (least aggressive) to Grade IV (most aggressive) based on histological and molecular characteristics. This grading system informs treatment decisions and recurrence risk. Brain tumours, particularly high-grade gliomas, are characterised by high rates of recurrence despite multimodal treatment approaches. Even with maximal safe surgical resection followed by radiotherapy and chemotherapy, most patients experience tumour regrowth within months to a few years, reflecting the infiltrative biology and resistance mechanisms of these cancers [10], [11]. For example, a Grade IV glioblastoma has recurrence rates approaching 90%, often requiring multimodal treatment including surgery, radiotherapy, and chemotherapy [12], [13].

Recurrence is associated with worsened prognosis, reduced quality of life, and limited therapeutic options, as second-line treatments are typically palliative rather than curative [14], [15]. Recurrence not only exacerbates clinical complexity but also imposes significant burdens on carers and health systems, with informal care **estimated at 3.7 million hours** annually in Australia [1]. These realities highlight the urgent need for improved surveillance protocols, targeted therapies, and coordinated survivorship care models.

Informal care of brain cancer patients is estimated at **3.7 million hours** annually in Australia, exacerbated by cancer recurrence

Brain tumours are the leading cause of cancer-related death in children

In children, brain tumours are the most common solid cancers and the leading cause of cancer-related death [16]. Approximately 60% of paediatric brain tumours arise in the posterior fossa, affecting the cerebellum and brainstem, regions critical for motor coordination and vital functions [17]. Common paediatric tumour types include astrocytomas, medulloblastomas, and ependymomas, which are highly malignant with poor prognosis [18]. These tumours often present unique challenges due to the developing brain's vulnerability to treatment-related neurotoxicity, necessitating age-appropriate care pathways and psychosocial support [19].

Brain tumours in adults are complex and often chronic and incurable

In adults, the most prevalent malignant tumours include glioblastomas, oligodendrogliomas, and meningiomas, with gliomas accounting for a significant proportion of malignant cases [20]. A particularly complex subtype is the IDH-mutant glioma, which typically affects adults aged 20–45. These tumours are chronic and incurable, with patients enduring cycles of treatment and surveillance over 5–20 years. The unpredictable progression and high treatment burden contribute to significant cognitive, emotional, and physical impairments [21].

The complexity of brain cancers stems from their genetic heterogeneity, variable growth patterns, and location-specific symptoms. Tumours in sensitive brain regions (e.g., motor cortex, language centres) are associated with severe functional impairments. Treatment often leads to permanent brain injury, exacerbating cognitive decline and psychological distress [19].

Over 1,400 genes are implicated across brain cancer subtypes

Genetic profiling has revolutionised the classification, diagnosis, and treatment of brain cancers, particularly gliomas and glioneuronal tumours. With over 1,400 genes potentially associated with various brain cancer subtypes, any understanding of the patient's unique genetic profile may provide key insights [22]. The WHO CNS5 classification now mandates molecular testing alongside histology for accurate tumour grading and subtype identification [3]. This includes somatic gene panel testing for single nucleotide variants, structural variants, fusions, and copy number alterations, essential for both initial diagnosis and relapse management [23]. Key mutations such as IDH1/IDH2, 1p/19q co-deletion, MGMT methylation, and TERT promoter alterations are routinely assessed to guide prognosis and therapeutic decisions [24].

Emerging technologies, such as Oxford Nanopore sequencing, now enable intraoperative genetic classification of brain tumours within two hours, dramatically reducing diagnostic delays and improving treatment timelines [25]. These advances are particularly impactful in paediatric and high-grade adult gliomas, where early molecular insights can influence surgical strategy and adjuvant therapy selection. Furthermore, familial glioma studies have identified over 50 genes linked to inherited brain cancer risk, underscoring the importance of germline testing in families with multiple affected members [26].

Australia's Medical Services Advisory Committee (MSAC) has supported the listing of somatic gene panel testing on the Medicare Benefits Scheme (MBS), recognising its safety, cost-effectiveness, and diagnostic value [27]. However, access remains uneven, with many patients bearing out-of-pocket costs. A national framework for equitable genomic testing, integrated with biobanking and clinical trial infrastructure, is essential to ensure all Australians benefit from precision oncology in brain cancer care.

The devastating physical, emotional and social impact of brain cancer: A multifaceted burden beyond the clinical that contributes to the high economic costs of brain cancer

The physical impacts of brain cancer

Brain cancer presents a multifaceted burden that extends beyond survival outcomes, encompassing profound physical, cognitive, emotional, and psycho-social challenges. Physically, patients often experience neurological deficits such as seizures, motor impairments, and sensory disturbances, which can significantly reduce independence and quality of life. Cognitive decline is common in all cancer survivors, with up to 75% reporting issues with memory, attention, and concentration during treatment, and one-third continuing to experience these problems post-treatment [28]. In brain cancer patients, cognitive impairments are prevalent, with neurocognitive dysfunction reported in up to 91% of patients, depending on tumour type, treatment modality, and disease progression [29]. These impairments, ranging from memory loss and executive dysfunction to reduced attention and processing speed, can disrupt daily functioning, occupational roles, and interpersonal relationships. The presence of a tumour itself, particularly in sensitive brain regions, can directly affect cognition and behaviour, leading to personality changes and disorganisation that disrupt relationships and employment [30], [31]. Importantly, sociocognitive functioning, which includes the ability to empathise, interpret social cues, and resolve interpersonal conflicts, is increasingly recognised as a critical determinant of wellbeing and treatment outcomes [31].

The physical impacts of brain cancer mean patients rely on coordinated care from a broad range of healthcare professionals, including general practitioners (GPs), neurosurgeons, neurologists, radiation and medical oncologists, as well as allied health professionals like neuropsychology, physiotherapy and speech pathology [32].

The psychological impact of brain cancer

The diagnosis and treatment of brain cancer are associated with high levels of psychological distress. Research on participants with advanced cancer (any type) in Australian palliative care settings showed that almost half of all patients report symptoms consistent with depression and over one third with anxiety [33]. Brain cancer in particular can carry a psycho-social burden that extends to families and informal caregivers, who often face emotional exhaustion, financial strain, and social isolation. Surveys of brain cancer patients and their caregivers have indicated the rate of psychological distress within these groups can be equally high [34] and may not reduce over time [35]. In patients, these symptoms are often exacerbated by physical pain and discomfort, cognitive decline, and existential concerns, including fear of disease progression and loss of identity. Depression and the sense of being a burden have been identified as predictors of a desire for hastened death among terminally ill patients, underscoring the need for early psychological intervention [36]. Early palliative care may significantly reduce anxiety and improve quality of life, although its impact on depression and functional status remains unclear [37].

A devastating physical and emotional impact, yet support falls short

Despite the clear need, access to timely and integrated psychosocial support remains inconsistent across Australian healthcare settings, particularly for patients with non-malignant tumours or those outside metropolitan areas. Service availability can vary depending on tumour type, location, and clinical setting, with individuals diagnosed with benign tumours often receiving less or inconsistent support, and those with malignant tumours rarely accessing rehabilitation services [34].

The cumulative impact of cognitive decline, emotional distress, and social disruption necessitates a shift in care models from survival-focused approaches to holistic frameworks that prioritise quality of life, functional recovery, and psychosocial resilience. Systemic barriers such as staffing shortages, long waitlists, and lack of brain tumour-specific expertise further limit access to care. Addressing these needs requires multidisciplinary collaboration, investment in rehabilitation services, and the integration of psychosocial care into standard oncology pathways.

Case study: Loss of Driving Licence

Driving is not simply transport. For many people with a brain tumour, it is shorthand for independence, identity, and connection to work, family, and community. Yet in Australia, the safety-first framework of Assessing Fitness to Drive (AFTD) places brain tumours squarely within “space-occupying lesions,” alongside explicit standards for seizure disorders, vision, cognition, and other neurological functions that underpin safe driving. Clinicians are expected to advise patients to stop driving when risk is material, with driver licensing authorities empowered to set conditions or suspend licences, and patients legally obliged to disclose relevant health changes. These rules exist to save lives, but the way they are experienced can feel blunt: after diagnosis, surgery, or a seizure, patients are often told (abruptly and with little practical support) to hand over the keys. Even when a path back to the road exists, it typically requires medical clearance, an occupational therapy driving assessment, and sometimes car modifications or restricted licences, processes that can be confusing and prolonged without coordinated guidance.

The psychosocial toll of driving cessation is large, and often invisible. Losing a licence reshapes daily life and relationships, increasing reliance on carers, reducing access to work and healthcare, and amplifying isolation and distress. Australian guidance acknowledges that brain tumours and their treatments affect memory, planning, reaction time, perception, and mood, which are precisely the skills required to drive and the capacities that scaffold autonomy in everyday life. Recent advocacy work also describes how neurocognitive and emotional changes erode a person’s ability to self-advocate and navigate systems [21], with driving limitations compounding that loss of control. As such, fitness to drive decisions are not simply administrative footnotes to treatment, they are inflection points that can either protect dignity or deepen disadvantage.

Driving decisions should be treated as part of psychosocial care, not merely regulatory compliance. For example, screening for distress at the moment of licence loss, offering counselling and peer support, and planning alternatives that preserve agency.

Ruby Rae's Story

6/9/2016 – 1/3/2023

Our beautiful Ruby will always be the definition of perfect. She had long blonde curly hair that she was so proud of, as it nearly touched her bottom. She had a permanent smile on her face that always brought people joy. She had the ability to light up a room whenever she walked into it. Whoever met Ruby always commented on how lovely she was. She had the kindest heart that always looked out for others. She was pure magic.

"Unfortunately, the torturous nature of DIPG was out looking to sabotage Ruby."

We first noticed Ruby's symptoms roughly six weeks prior to her diagnosis. She woke up one night with a headache, her moods had changed, she looked pale, she was tired, dizzy, and losing fine motor skills. I repeatedly reported these symptoms to our GP and specialists at our local Paediatric Hospital, Queensland Children's Hospital (QCH). Ruby's prior diagnosis of bronchiectasis (a lung condition) was blamed for her new symptoms. Regrettably, Ruby's regular respiratory specialist was on leave when we saw the hospital's respiratory department. I urged the senior specialist on the day to please listen to me as I didn't think her most recent symptoms were due to her lungs.

"He dismissed my concerns and directly told me not to present to the emergency department as this issue would be solved with a PICC line insertion and strong antibiotics."

This was organised to occur within a fortnight. I thankfully documented this encounter and now look back and don't understand how he got it so wrong, why he didn't listen to me, why he didn't investigate my concerns more.

Her symptoms were neurological, not related to her lungs. While waiting for the PICC line, Ruby's symptoms increased. She couldn't enjoy her 6th birthday party she was so looking forward to; she didn't feel right. I was still reporting these symptoms to our GP and hospital. The night before Ruby lost the ability to walk straight, she dropped her plate after dinner. She was noticeably frustrated and upset with herself, rightly so, as she was losing the ability to be a child. I comforted her and added it to my never-ending list of symptoms that doctors had disregarded for nearly two months.

"The following day we went to the beach, Ruby couldn't walk; each step she took she fell."

It was heartbreaking; I recorded it to show doctors. This was my final straw. I immediately took her to the Sunshine Coast Hospital as we were visiting there. At first, once again, my concerns were being dismissed, then a junior doctor took the time to listen to me. He pushed to get an emergency MRI. After the MRI, I thought it was odd how nice everyone was being to us. Hours later, a senior doctor asked to speak to me; she was holding a box of tissues, I knew what that meant. I was escorted to a private room where I was told, "Ruby has a large mass on her brain." I screamed. Once again, no answers could be given. We were transferred to Brisbane's QCH that night. On arrival at QCH, I was having a panic attack. I was unable to walk, breathe, or talk, I needed a wheelchair. My aunt met us at the hospital as my husband stayed with our 3-year-old at the coast. Due to COVID restrictions, my aunt wasn't able to enter the emergency department, I was left alone. Alone with a scared, tired, confused, and sick child. The following morning, our family was able to visit. We still knew nothing. Hours passed until we met with the neurosurgeon who told us her brain tumour was inoperable.

When I asked further questions and specifically asked, "Is my daughter going to die?" he put his hand up in my face and firmly said, "Stop, we are stopping the conversation here." I was shut down once again.

"We waited another six hours to see an oncologist. We were told Ruby had the deadliest cancer and to go make memories. No successful treatment, no options, no hope."

We were asked if we wanted to do a biopsy on her tumour directly after this news. A biopsy would inform us what gene marker the tumour contained. However, it is a seriously dangerous procedure that other children have been severely disabled from, and some died from it. This wasn't a risk we wished to take, so we declined. This one brief traumatising encounter with the oncologist was the only conversation we had with him for the next two weeks as he went overseas. We were left in limbo, knowing our child was dying without any answers.

When he did return, I received a phone call, five hours delayed. It was brief, short, and rushed. Once again, not listened to, and all my questions left unanswered.

A week later, we had an in-person appointment with our oncologist before we started palliative radiation. He ran two hours late; we had to leave and miss our appointment due to Ruby needing to be at radiation. Once again, no answers. When we finally did meet with our oncologist after multiple complaints to the hospital about our treatment, I was once again shut down when asking about clinical trials and just generally wanting information. I made further complaints to the hospital and health minister; this still didn't give me the answers I was looking for. We once again had an appointment with our oncologist who told us he was leaving for an extended period of time. During this appointment, he told Ruby she had a brain tumour, after I had specifically requested for this not to be mentioned or spoken about in front of her. This was documented in all patient notes, and I always brought another person with me so Ruby could be taken out of the room when we needed to talk about her diagnosis.

“I was mortified. My daughter had the deadliest childhood cancer and no oncologist. He just told her she had a brain tumour. There was no contingency plan; we were doctorless.”

After making further complaints, we fortunately struck gold and got an oncologist who was compassionate, listened, and genuinely cared about Ruby. Our new oncologist met with us weekly, then fortnightly. I was able to openly run ideas by him; he advocated for Ruby’s needs and treated her like the beautifully innocent child she was. As we opted not to do a biopsy of Ruby's tumour due to safety concerns, we were ineligible to enrol in clinical trials. This meant we were forced to buy a trial drug from Germany for $20,000; this was only for three months' worth. When this arrived in Australia, we then had to pay a 10% tax upon the $20,000 we had already paid. We paid this amount twice, totalling roughly $45,000.

Besides these costs, we had to pay for all her extra medical expenses, aids, adjustments to our house, and therapies. Therapies consisting of hydrotherapy and music therapy, aids to help with fine motor skills, ASO and AFO ankle braces, house adjustments to help Ruby mobilise, shower and toilet.

Unfortunately, a wheelchair wasn’t able to be purchased, Ruby had to use her sister’s pram, this was the only option we had to get her out of the house. In a letter written from QCH's senior oncology occupational therapist, she stated, "We do not routinely support the application for the NDIS for patients with Ruby’s diagnosis because it takes a long time for the process to be completed and to be able to access therapies."

“She may as well have said Ruby is going to die before her application is approved. This was just another systematic failure.”

On the 1st of March 2023, Ruby called out at 2 am, "Mummy, mummy!!" I rushed in; she was holding her head and complained of a major headache. I quickly called palliative care; they advised to give her medication, I did so. She started to vomit and roll around in agony; I called palliative care again, they advised to give more pain medication. She then became unconscious, her breathing slowed. I called an ambulance thinking I had overdosed her. She was intubated in her bed where she had slept her whole childhood. Our 3-year-old was asleep in the room next door, not knowing her sister was dying. We rushed to QCH where an MRI showed Ruby had devastating complications of DIPG. She had hydrocephalus, leptomeningeal spread, and meningitis.

“My poor innocent child, just 6 years old, had been tortured for the past five months. It was time she rested and had a chance to be at peace.”

We chose not to wake Ruby up from the induced coma she was in. She didn't need to be traumatised more. In one final act of kindness, Ruby donated her tumour to research, in hope to save other children. Ruby was transferred to Hummingbird House, where she would pass away.

“Losing a child is the worst grief anyone can experience. However, ours was compounded by medication complications and organisational errors.”

Hummingbird House ran out of the medication Ruby needed to help keep her comfortable while she passed away. An on-call doctor had to be called in out of hours to write a script. This script then had to be processed externally, taking nearly four hours.

During this time, we listened to Ruby’s "death rattle" increase and worsen. Once the needed medication arrived, Ruby soon after passed at 11:58 on the 1st of March while in my arms.

For Ruby to donate her tumour after she passed, she needed to be transferred to the Royal Brisbane Hospital Tumour Bank. This was previously organised while at QCH, and I was told this would occur the following morning.

Throughout the night, I confirmed with the Hummingbird House staff that this was still occurring. I was reassured multiple times that it was correct. This was so important to me as it meant Ruby was able to donate her tumour in the morning, then be cremated, then returned to me by the afternoon. Devastatingly, this isn't what happened.

“Due to communication and organisational errors, Ruby was taken from us twice. My husband carried her lifeless body onto a stretcher twice.”

We were given the option of Ruby donating her tumour then staying in the Royal Brisbane Hospital morgue for the night then being cremated. Or doing tumour donation then Ruby returns to us at Hummingbird House. We opted for the second option. Due to this, she had to be placed in a cold room, one like at the bottle shops, with the big sliding doors. It was made into a room with a temperature of four degrees. She laid on dry ice that needed to be regularly changed to keep her cold. I still have nightmares of how cold she was; I picture myself hugging her and breaking her neck due to her being frozen. The following morning after she returned to us, she was taken again, this time to be cremated. For one last kick in the guts, we were told there were no urns in the whole of Brisbane that would fit Ruby's ashes. We spent the whole day pleading and trying to find something she could be placed in. We found a jar; it wasn't perfect, but it was something. This is where she rests surrounded by all her favourite things and photos in our lounge room. Our story is traumatic, but it is our real life, just like so many others in Australia. This is DIPG. It is the deadliest childhood cancer that everyone says is too rare; it won't happen to you.

“Being a paediatric nurse myself, I never thought I'd be watching my own child die. I plead for you to say Ruby's name, to remember her beautiful long curly hair, her smile, and her pure love for life. She deserved to live a full happy life. Please, we need to fund DIPG research to save our children.”

Forever Ruby's Mum,

Hannah Pringle

The economic impact and burden of brain cancer

Without change, the burden of brain cancer will continue to grow

By 2050,

23,352 Australians are expected to be living with brain cancer

2,650 Australians are expected to die each year with brain cancer

3,200 Australians are expected to be diagnosed with brain cancer per year

Source: Biointelect analysis [1]

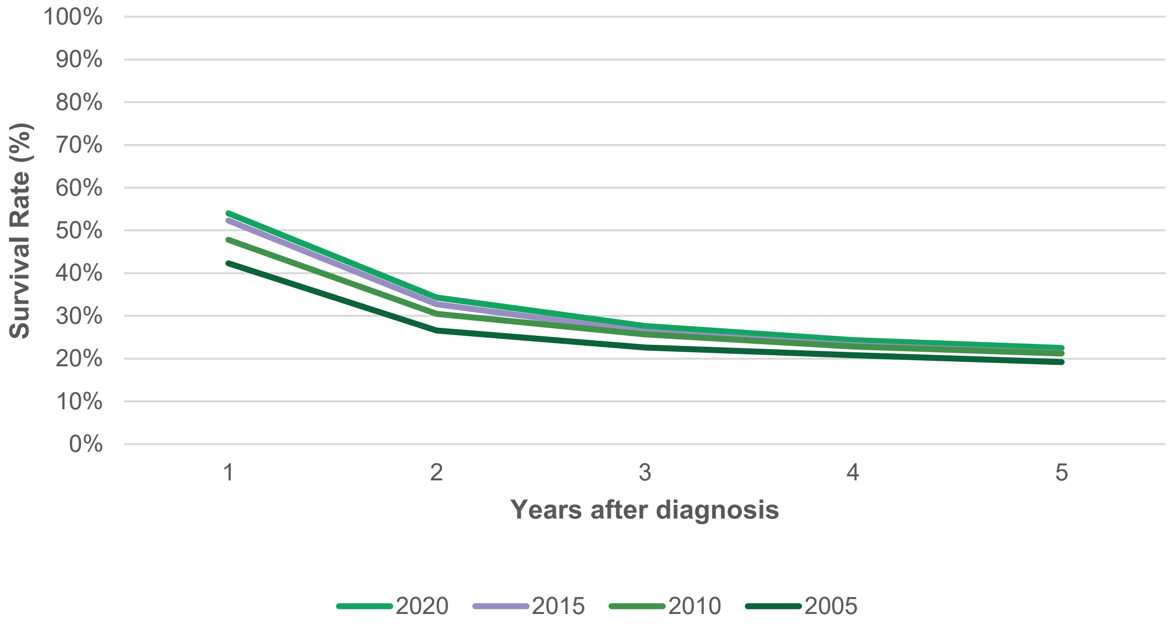
Both incidence and mortality rates for brain cancer have remained relatively constant over the last 20 years in Australia [2]. Assuming a similar pattern over the next three decades in line with current population growth in Australia, more than 23,000 patients are expected to be living with brain cancer in the year 2050, with approximately 2,650 deaths expected each year. Brain cancer kills more Australians under 40 years of age than any other cancer and more children than any other disease [38].

Currently, one person is diagnosed with brain cancer in Australia every five hours; this equates to approximately 2,000 patient diagnoses each year [38]; this figure will increase by 2050 with more than 3,200 new diagnoses expected each year [1]. Some lower-grade brain tumours can be managed long-term and are not always immediately life-threatening [39]. Fortunately, their recurrence can sometimes be prevented. It is possible for people with low-grade or surgically resectable tumours to live for many years and, in some cases, to be considered effectively cured [40]. However, most high-grade brain cancer diagnoses are incurable, recurrence is inevitable, and current treatments only delay progression and death [41].

Brain cancer has one of the lowest improvement rates (~4%) in **5-year overall survival data** of all cancer types over the last three decades

While survival time can vary by diagnosis, Figure 3 shows that the overall 5-year survival data for brain cancer has, for the most part, remained relatively unchanged. In 2015–2019, individuals diagnosed with brain cancer had a 23% chance (22% for males and 25% for females) of surviving for five years compared to their counterparts in the general Australian population [5]. A negligible improvement from 19% relative survival in those diagnosed nearly 30 years prior, in 1990-1994 [5].

Figure 3: Survival rates from year(s) after diagnosis in years 2005, 2010, 2015, 2020 (All ages combined)

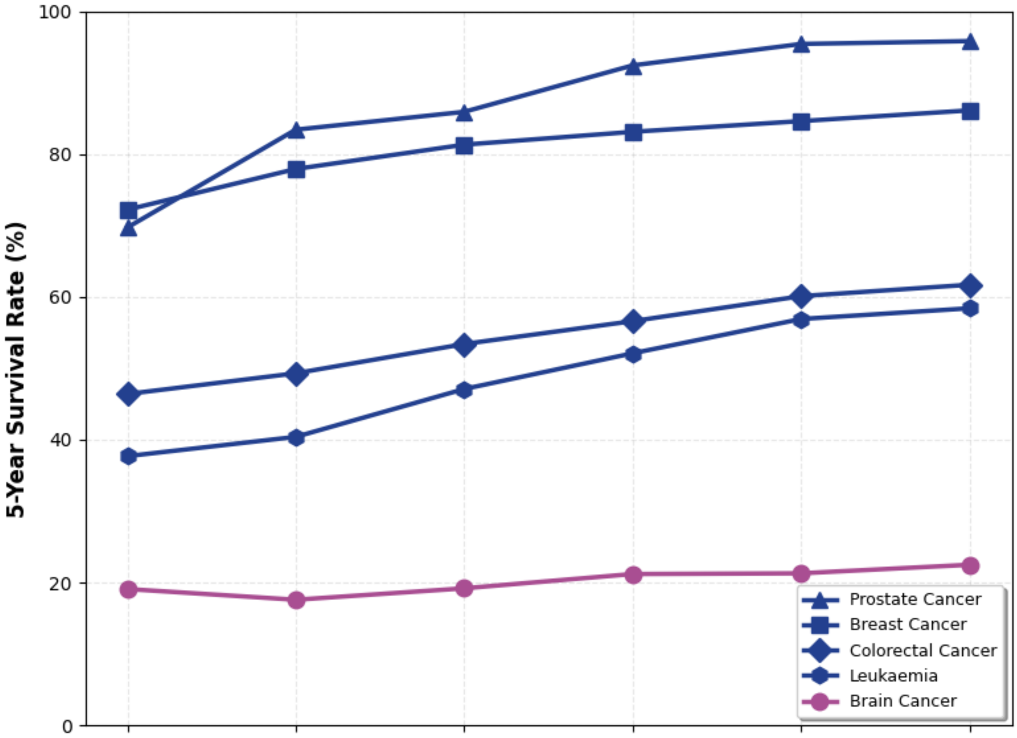


Source: Australian Institute of Health and Welfare [2]

Brain cancer outcomes worsen, while other cancer outcomes continue to improve

The 5-year survival rates of other cancer types have observed a pronounced increase in the last 30 years. Individuals diagnosed with prostate cancer between 2016 and 2020 had a 96% chance of surviving for five years compared to their counterparts in the general Australian population, an increase from 70% in 1991–1995 [42]. Similar improvements were seen in breast cancer (79% to 92%) [43], leukaemia (43% to 64%) [44] and colorectal cancer (56% to 71%) [45], as shown in Figure 4.

Figure 4: 5-year survival rates across different cancer types, from 1991 to 2020.



	1991-1995	1996-2000	2001-2005	2006-2010	2011-2015	2016-2020
Prostate Cancer	69.7	83.4	85.9	92.4	95.4	95.8
Breast Cancer	72.2	77.9	81.3	83.1	84.6	86.1
Colorectal Cancer	46.4	49.3	53.4	56.6	60.1	61.7
Leukaemia	37.7	40.4	47.1	52.1	56.9	58.4
Brain Cancer	19.1	17.6	19.2	21.2	21.3	22.5

Source: Australian Institute of Health and Welfare [2]

Brain cancer imposes a significant burden on patients' quality of life and Australia's health care system

Few diseases affect lives as profoundly as brain cancer does. In 2025 alone, all brain cancers are expected to result in **38,536 years of life lost** due to premature death, averaging at 22.7 years per patient. An additional 4,249 years of healthy life were lost to disability, bringing the total burden to **42,784 DALYs** lost [1]. These figures demonstrate the impact of brain cancer on both individual potential and broader societal progress, with a marked effect on younger, economically active people.

In 2025 alone, brain cancers are projected to result in:

38,500 years of life lost due to premature death (averaging 22.7 years per patient)

4,250 years of healthy life lost due to disability

42,750 disability-adjusted life years (DALYs) of healthy life lost due to disability

Source: Biointelect analysis [1]

Brain cancer has profound costs to society

Predicted loss of productivity (paid economic activity) due to a brain cancer diagnosis for affected individuals is approximately a loss of **$251.3 million** to the Australian economy in 2025 alone. Associated predicted loss of productivity due to care giving for a brain cancer patient in 2025 is an additional loss of approximately **$153.1 million.**

The economic impact of this often-overlooked cancer is substantial and is projected to increase. According to Biointelect analysis, the total societal cost is conservatively estimated at **$0.85 billion** in 2025, rising to **$3.2 billion** by 2050, if current trends continue [1]. These costs encompass treatment expenses, productivity losses, and supportive care costs including aged care packages, all of which place growing pressure on healthcare systems, government budgets and individual households.

This financial strain underscores the urgent need for streamlined care pathways, greater investment in research, and the development of innovative therapies to help curb the escalating burden.

Total societal cost of brain cancer estimated to be **$3.2 billion** by 2050

Source: Biointelect analysis [1]

Of all cancer types, brain cancer drives the greatest healthcare spend

Low-survival cancers are defined as those with a five-year relative survival rate between 0% and 35%. This group includes cancers of the liver, pancreas, lung, oesophagus, stomach, unknown primary site, and brain. Among these, brain cancer has one of the lowest survival rates and the highest mean annual healthcare cost per person [46]. Consequently, brain cancer exhibits the least favourable ratio of per-patient healthcare expenditure to overall survival outcomes. In 2025, healthcare-related costs for brain cancer patients are projected to impose a substantial economic burden of **$313 million** or an average of **$29,963** per affected individual [1]. This figure is significantly higher than the overall mean annual healthcare cost per person of $15,889, estimated for all cancer types [46].

Ongoing brain cancer treatment will cost Commonwealth, State, and Territory governments an estimated **$313 million** in 2025

Source: Biointelect analysis [1]

Factors fuelling the escalating costs of brain cancer

Systemic inefficiencies, including repeated GP consultations, emergency department (ED) visits, and delays in diagnostic testing, can contribute to late-stage diagnoses and escalating costs [47]. The disease requires regular treatment and magnetic resonance imaging (MRI) monitoring for malignant changes, causing ongoing financial strain on health system budgets. These factors underscore the urgent need for policy-level interventions aimed at streamlining diagnostic pathways, improving access to imaging services, and investing in early detection strategies to mitigate long-term expenditure.

The broad needs of a patient with brain cancer: National Disability Insurance Scheme (NDIS), aged care and allied health support requirements

Average NDIS Participant funding (based on data collected by NAS)

Since its inception in 2021, the NAS has supported approximately 3,000 individuals diagnosed with brain cancer, with referrals steadily increasing year-on-year. Annual referral figures grew from 89 in 2021, to 356 in 2022, 556 in 2023 and 731 in 2024. Projections estimate that referrals will rise to 1,000 by the end of 2025 [48]. Of those supported by the NAS, 484 individuals were aged over 65 and therefore ineligible for the NDIS. Among the 1,746 age-eligible referrals, 592 patients have successfully accessed NDIS support.

The average value of a NDIS plan for a brain cancer patient is $221,000, with 88% of plan values exceeding $100,000, and 56% exceeding $200,000, with the highest recorded plan value being $907,000.

The average value of a NDIS plan for brain cancer patients is over **$221,000**, with 88% exceeding $100,000 and 56% exceeding $200,000

Source: Biointelect analysis [1]

Aged Care

A Level 4 Home Care Package is for individuals with high-level, complex care needs, offering a significant government subsidy to provide extensive support at home [49]. This funding allows for comprehensive services such as daily personal and nursing care, medication management, allied health, and support for memory or behaviour changes. The specific amount of funding, upwards of approximately **$63,758** annually for level 4 individuals [50], is used to create a care plan to meet the applicant's unique needs. Brain cancer patients aged 65 years and above are potentially eligible for this package; currently this demographic constitute approximately **49.3%** of the overall incident brain cancer population [51]. With Biointelect analysis forecasting more than 1,000 diagnoses in this demographic from 2025 onwards, (coupled with surviving patients from younger demographics), this has the potential to have a significant impact on the Commonwealth Government budget, to the extent of hundreds of millions annually [1].

The increasing number of new diagnoses in those aged 65+ coupled with aging surviving patients could cost the Commonwealth Government **hundreds of millions of dollars annually**

Source: Biointelect analysis [1]

The economic and societal costs of brain cancer to patients, caregivers, communities and government are profound. Brain cancer imposes a uniquely heavy burden on both individuals and the healthcare system in Australia. The high direct healthcare costs, coupled with the need for ongoing support through aged care, NDIS, and allied health services, reflect the complex and persistent demands of this disease. Beyond the economic impact, brain cancer profoundly affects patients’ independence, cognitive functioning, and emotional wellbeing, with significant ripple effects on families and caregivers.

The cost of systemic underinvestment in brain cancer

Australia currently faces a significant lack of public and governmental awareness about brain cancer, contributing to systemic underfunding of essential research and no dedicated government funding to date for brain cancer support services. Persistent survival stagnation, high per-person costs, and heavy hospital use sit alongside chronic underinvestment and structural barriers in research and care. This disparity severely limits advancements in treatments, leaving survival rates virtually unchanged for decades. The result is a pronounced spend-to-survival mismatch that has constrained progress for decades.

Direct research funding for brain cancer has consistently lagged behind other cancers

From 2003 to 2020, brain cancer received $111.6 million in total project funding, well below breast cancer ($431.6 million), leukaemia ($234.7 million), colorectal cancer ($190.8 million), prostate cancer ($184.7 million), and melanoma ($175.5 million) [52]. Although investment in brain cancer rose more than thirty-fold, predominately through the ABCM, from $1.5 million in 2003-05 to $54.1 million in 2018-20, it remained materially lower than leading cancer types in the most recent period – breast cancer $91.3 million and leukaemia $67.9 million. This cumulative shortfall, despite a late uptick, indicates structural underinvestment that has contributed to constrained discovery, translation, and clinical impact.

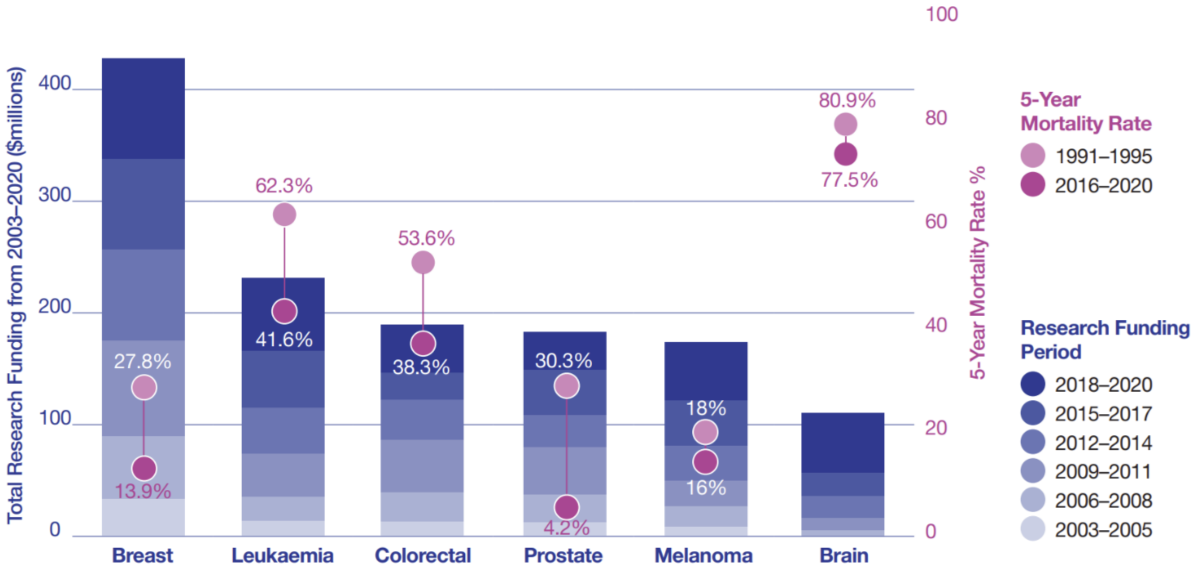
Table 1: Direct funding to cancer research projects from 2003–2005 to 2018–2020 ($millions)

	2003-2005	*2006-2008*	*2009-2011*	*2012-2014*	*2015-2017*	*2018-2020*	*Total*
Brain	$1.5	$4.9	$11.3	$20.0	$19.8	$54.1	**$111.6**
Breast	$33.4	$57.4	$85.9	$81.7	$81.9	$91.3	**$431.6**
Leukaemia	$15.3	$20.8	$39.7	$40.5	$50.5	$67.9	**$234.7**
Melanoma	$8.5	$19.1	$24.6	$29.2	$41.8	$52.3	**$175.5**
Colorectal	$13.6	$26.7	$47.2	$36.0	$23.7	$43.6	**$190.8**
Prostate	$13.2	$25.8	$41.6	$28.7	$41.2	$34.2	**$184.7**
Ovary	$2.2	$7.2	$11.7	$16.4	$25.4	$31.2	**$94.1**

Source: Cancer Australia [52]

The recent increase in funding, a large part of which can be attributed to the ABCM's commitment of $133.66 million, has been necessary but not sufficient. Unlike several other cancers, brain cancer research has lacked the enabling infrastructure that accelerates progress; for example, coordinated biobanking, population-scale registries with rich clinical and molecular data, and interconnected clinical trial networks that support timely, equitable recruitment and rapid translation. These scientific and operational barriers are compounded by limited public awareness, weaker advocacy momentum, and scarce corporate partnerships. The disease disproportionately affects younger populations who may have less political influence, and its neurological effects can impair patients' capacity to advocate for themselves. In the care setting, fragmented pathways and constrained access to psychosocial support increase the burden on patients, carers, and families, and contribute to reduced workforce participation, long-term disability support needs, and higher system costs.

Figure 5: Long-term trends in cancer research funding compared to 5-year mortality rate in major cancer types



Source: Funding data from Cancer Australia [52]*; Survival data from Australian Institute of Health and Welfare* [2].

The funding-cost paradox in brain cancer

The disparity between research investment and long-term healthcare expenditure for brain cancer is apparent, as highlighted in a recent Australian cancer survivorship study investigating patients up to 19 years after diagnosis [46]. The research, performed in Queensland from 2013 to 2016, discovered that people with brain cancer recorded the second highest mean annual healthcare expenditure per person at $30,264, almost double the cohort-wide average across all cancers at $15,889. Notably, most costs were driven by hospitalisations. A total of 64.8% of people with brain cancer were admitted to hospital compared with 48.6% across the full study cohort.

Despite brain cancer patients incurring the second highest mean annual healthcare cost of all cancers, research funding has remained among the lowest of major cancers. By comparison, breast cancer has attracted the highest cumulative research investment yet reported a substantially lower annual cost burden of $13,140 per person. Similarly, health expenditure costs for colorectal cancer ($17,858), melanoma ($9,487), and prostate cancer ($13,119) were all well below brain cancer. Leukaemia, which has received more than double the cumulative research funding of brain cancer, still had a slightly lower annual cost at $29,158 per person. This imbalance underscores a structural inequity in that the cancer type generating some of the highest per-patient costs and poorest survival outcomes receives disproportionately low research investment, limiting opportunities to reduce both clinical and economic burden.

Health expenditure costs for colorectal cancer, breast cancer, melanoma, and prostate cancer are estimated to be well below brain cancer

Despite this, brain cancer has received the lowest cumulative research funding among these cancers

A structural oversight in prevention and early detection

Australia's prevention-focused cancer control paradigm has delivered substantial gains where national programs exist. Breast, cervical, and bowel cancers benefit from coordinated screening strategies that improve early detection and survival. Whilst brain cancer does not meet public health criteria for population-based screening, increased public awareness and enhanced healthcare professional awareness and education would lead to earlier diagnosis, potentially minimising the challenges that come with treatment of late-stage disease. Patients typically present symptomatically, often after tumours have progressed beyond optimal treatment windows. Although the blood–brain barrier and tumour heterogeneity pose genuine biological challenges, these do not fully explain the survival gap. Emerging work on blood-based biomarkers and advanced imaging suggests earlier detection could be feasible. Yet Australia lacks a coordinated strategy to develop, validate, and implement such approaches within a learning health system that integrates discovery with clinical practice.

Without urgent action to align investment with disease burden and to build the infrastructure that converts funding into lives saved, Australians with brain cancer will continue to face the same prognosis they did decades ago, despite steady investment and promising scientific advances.

Decades of limited progress in brain cancer treatments

Despite significant advances in most areas of oncology, progress in developing effective treatments for brain cancer has been limited, as reflected in the absence of any more effective therapies being developed within the past three decades. The lack of progress has been attributed to numerous factors, including inherent biological challenges, inefficiencies in research pipelines, and the multifactorial complexity of these conditions [53].

Clinical trials hold promise, but remain out of reach for many

Access to experimental treatments through clinical trials represents one of the few avenues for hope, yet significant barriers prevent many Australians from participating in potentially life-saving research. A survey of Australian neuro-oncology professionals identified lack of funding for international trials and insufficient research time as the most commonly cited barriers to clinical trial participation [54]. Geographical inequity compounds these challenges, with 89% of cancer treatment trials having sites only in major cities or inner regional areas, while 39% of Aboriginal and Torres Strait Islander peoples live outside these areas. For rural patients specifically, barriers include timely access, monetary burden, commute requirements, and lack of information about available trials. The regulatory complexity further complicates access, with patients needing to navigate multiple pathways to access new medicines before they are registered on the Pharmaceutical Benefits Scheme (PBS) or approved by the Therapeutic Goods Administration (TGA). Moreover, the lack of trials in Australia involving advanced therapeutics, such as cellular therapies, may limit effective outcomes.

While the Australian Government has recognised these challenges through initiatives like the ABCM, the pipeline of promising treatments remains limited, with most new approaches still in early-phase trials and facing the fundamental challenge that very few existing drugs can cross the blood-brain barrier. The predominance of pharmaceutical company-sponsored trials (92% of brain cancer trials in Australia) also means that access often depends on commercial priorities rather than patient need, further limiting treatment options for this vulnerable population.

Jack's Story

"Brain cancer kills more Australian children than any other disease. It also kills more people under 40 in Australia than any other cancer."

I didn't know this and naively thought leukaemia was the number one killer of children in Australia. Unfortunately, I had a brutal awakening which started early evening on Saturday 28 May 2016.

Jack, who was 19 at the time, complained of a headache. My wife, Dianne, told him to take a couple of Panadol and lie down. We didn't think anything of it other than a little unusual as Jack had never complained of headaches previously.

That night he had his first seizure and spent the night in hospital under observation.

After several exploratory tests over the next couple of months which included a biopsy on 6 July, we were asked to meet with his neurosurgeon, Andrew Hunn, on 8 July.

Andrew asked Jack to sit close to his desk and nearest to him. He then pulled his chair around the table and sat directly in front of him.

The BOMBSHELL. "I am afraid I have bad news for you Jack and wished there was some other way to tell you, but you have brain cancer, and it is terminal. It is called glioblastoma multiforme or GBM and it is Stage 4."

"Jack didn't say a word. I could hear Dianne's breathing but not my own, as I had stopped breathing. I said, "how long…?" He said a year, give or take a month or two."

We got 22 months, and during that time I reached out to, and spoke to, many clinicians locally and around the world including Dr Patrick Wen, Professor of Neurology at Harvard Medical School.

I had moments of absolute despair, but Jack said all I want to do is live, and I knew I would do everything in my power to make that happen. But I didn't and I couldn't and as a parent I felt my greatest failing was the inability to prevent the death of my child.

I was told he wouldn't survive from day one by almost every clinician, but I thought I would figure it out as I always figure it out. When faced with a problem I solve it, simple. But this was a whole new level and for all my smarts, intuition, intelligence, education, and sheer adrenaline driven passion, this was only going to end one way.

But we had hope and one chance meeting with a Professor at Sydney University provided a glimmer of light where previously there was only darkness. Professor Manuel Graeber (Barnet-Cropper Chair of Brain Tumour Research, Sydney University) said he was surprised that someone so young was diagnosed with such an aggressive form of brain cancer (GBM) and suggested that he would like to undertake some tests to confirm the diagnosis, if I agreed.

He collaborated with Dr Michael Buckland (Head of the Department of Neuropathology, Royal Prince Alfred Hospital, Sydney) and conducted molecular testing of Jack's tumour, a procedure that is not readily accessible or used in Australia as part of brain cancer diagnosis. What that testing revealed was significant and although it confirmed the original diagnosis, it also identified a number of factors and unique markers that led to a new treatment regime and access to – on "compassionate" grounds - a unique antibody drug (ABT414).

"Whether it made any difference we will never know but at least we thought we had a shot and as a parent with Armageddon banging on the front door, we took our chances."

And during this time and with new found hope, I co-founded a whisky company and in which Jack became a small investor. My hope, lame now in hindsight, was that as his intelligence and mental processes would be compromised if he did survive, if I could give him a career in an industry he loved, it was worth a shot.

When Jack died, I sold our shares in the whisky company although my business partner and the new owner dedicated the first barrel of whisky to Jack, to be bottled and auctioned to raise money for brain cancer.

I also wrote a book – Jack's Story. It was never meant to be a fairy tale as I wanted everyone who would listen to understand that unless we find a solution, many children will follow Jack and many parents will suffer the same miserable fate that we experienced. It is a one-way march into Hell and there is no way back.

Leukaemia, breast, cervical, prostate and bowel cancers, amongst others, have experienced major breakthroughs in recent years and are no longer death sentences. However, "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 …"

Since Jack died, I have been collaborating with Royal Prince Alfred Hospital (Sydney), Sydney University (Brain Tumour Research Brain and Mind Centre) and Sydney Local Health District, to establish a molecular testing facility in Sydney for brain cancer patients.

Ken –

Jack's Dad

jacksstory.com.au

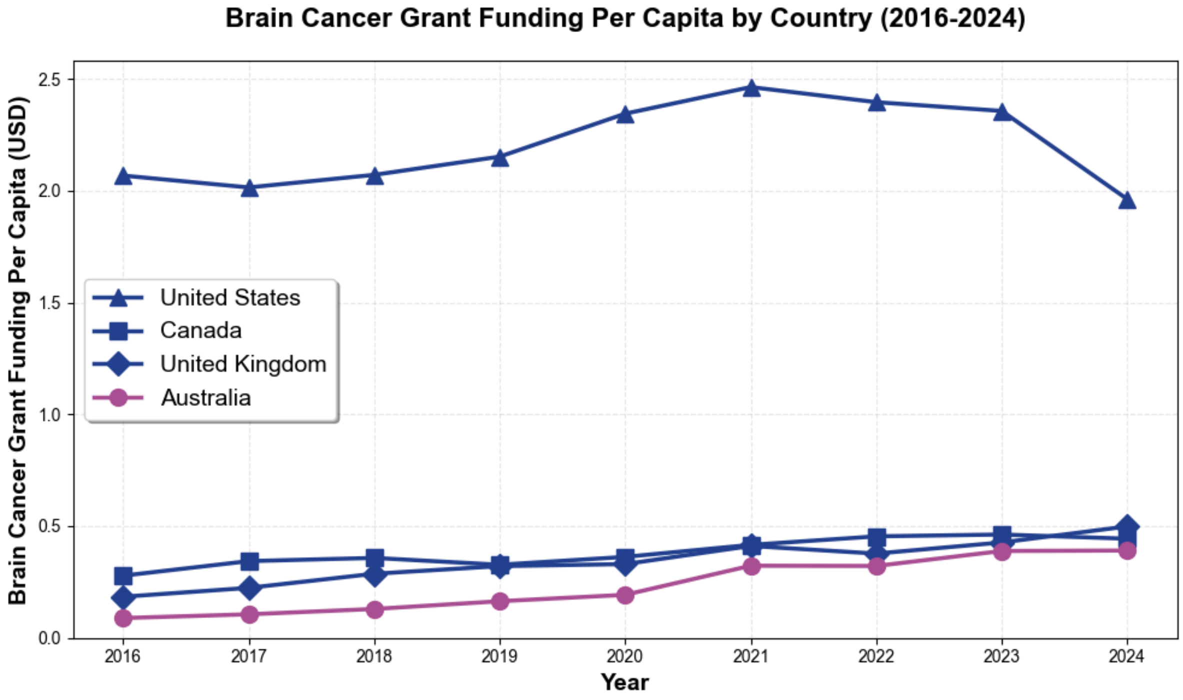
How Australia compares: International comparisons and best practice examples

Australia’s modest national commitment, compared to global initiatives

Compared to other nations, Australia's commitment and funding for brain cancer research and patient support have been comparatively modest. In the United States (US), initiatives such as the Cancer Moonshot and substantial investments from the National Cancer Institute (NCI) have significantly advanced brain cancer research, prioritising innovative treatments and fostering collaborative networks across institutions. Similarly, the United Kingdom (UK) has established dedicated Brain Tumour Research Centres with substantial funding from entities like Cancer Research UK and Brain Tumour Research, greatly enhancing targeted research and clinical trials.

In contrast, Australia's current level of funding and strategic national coordination remains limited, lacking sustained long-term investment and comprehensive support mechanisms comparable to international benchmarks. Figure 6 illustrates the discrepancy between per capita funding in Australia compared to the major western countries, where Australia has only recently caught up to the UK and Canada but still lags far behind the US. This discrepancy highlights the urgent need for Australia to increase its funding and strategic focus, aligning more closely with global standards to better address the complex needs of brain cancer patients and their families.

Figure 6: Funding for brain cancer over time in the USA, UK, Canada, and Australia ($USD per capita)



Source: Brain cancer funding data extracted from Dimension.ai [55]*; Population data from United Nations Department of Economic and Social Affairs* [56]. *Population adjusted per year.*

Case Study: United States – Excellence in Research

The United States demonstrates global leadership in brain cancer research through the Cancer Moonshot initiative and substantial NCI investments that have significantly advanced treatment options worldwide [57]. With annual budgets exceeding billions of dollars specifically allocated to cancer research, the US has created a robust infrastructure supporting everything from basic laboratory research to large-scale clinical trials [58]. This sustained funding model enables American institutions to attract leading researchers, foster collaborative networks across multiple institutions, and accelerate discovery.

The NCI's strategic approach has produced breakthrough treatments including CAR-T cell therapies adapted for brain cancers, novel drug delivery systems crossing the blood-brain barrier, and precision medicine approaches tailored to individual tumour genetics [59]. World-class institutions such as Johns Hopkins, Dana-Farber Cancer Institute, and Memorial Sloan Kettering Cancer Centre have developed comprehensive programs seamlessly integrating research with clinical care, ensuring laboratory discoveries rapidly translate into patient benefits [60]. The competitive grant system creates an environment where only the most promising research receives funding, whilst international partnerships through initiatives like the Brain Tumour Research Collaborative amplify research impact globally, demonstrating how strategic investment combined with collaborative networks positions a nation as a global disease-fighting leader [61].

Case Study: United Kingdom – Coordinated care

The UK represents a strong standard for coordinated brain cancer clinical care, with the National Health Service (NHS) providing comprehensive coverage to over 60 million people through a unified network ensuring equitable access to expert treatment. The Tessa Jowell Brain Cancer Mission has revolutionised clinical care coordination, with nine NHS centres achieving Centre of Excellence status following rigorous assessments based on clinical practice excellence, patient quality of life focus, and research standards [62]. Critically, patient insight was central to this process, with feedback from 880 patients ensuring excellence was measured by both clinical metrics and patient experience [62].

The UK's clinical innovation is exemplified by the world-first 5G platform trial launched in Cambridge and London, an adaptive early phase clinical trial where treatment selection is based on individual cancer genetics, with real-time data incorporation optimising protocols [63]. This design allows treatments from other cancer types to be rapidly tested in brain cancer patients. Brain Tumour Research Centres of Excellence have received over £8 million in funding, integrating artificial intelligence and machine learning with drug discovery expertise [64]. The coordinated approach extends to national specialist service coordination, standardised training programs, and systematic quality improvement, resulting in some of the world's best brain tumour survival rates whilst establishing the UK as a clinical care delivery leader.

Case Study: Canada – Comprehensive patient support

Canada delivers comprehensive patient support through universal healthcare designed to address medical, psychosocial, educational, and advocacy needs of brain cancer patients and families. The Brain Tumour Foundation of Canada provides national support services including monthly support groups, a toll-free support line, annual conferences, and 24/7 online Virtual Support Centre, ensuring no patient faces diagnosis alone [65]. Educational materials are available in English and French, in adult and paediatric versions, whilst Facebook support groups provide round-the-clock community support.

Canada's innovative funding model sees Health Canada matching private contributions up to $200 million by 2024-25, enabling $23.4 million allocation for brain health research and support [66], [67]. The Canadian Cancer Society's $17.9 million Breakthrough Team Grants specifically incorporate people with lived cancer experience as key research participants, ensuring research priorities reflect patient needs [68]. Recent initiatives include psychedelic-assisted cancer therapy for treating anxiety and depression in advanced cancer patients. The volunteer-driven Brain Cancer Canada model, where team members affected by brain cancer ensure maximum funds reach research, demonstrates effective grassroots advocacy [69]. Ontario's Cancer Plan 2024-2028 provides coordinated patient-centred care emphasising equity and integrated support services throughout the cancer journey, showcasing how universal healthcare can deliver comprehensive support addressing not only tumour biology but psychological and social impacts [70].

These international examples demonstrate that brain cancer excellence requires sustained commitment across research innovation, clinical care coordination, and comprehensive patient support. Each approach offers valuable lessons for Australia to enhance its brain cancer capabilities to match international standards and better serve patients and families affected by this devastating disease.

In Memory of Brandon Schrader

Our young family's ordeal with Glioblastoma Multiforme Grade 4, Terminal Brain Cancer.

An introduction to my family, my name is Shae Jones and 4 years on, I am now 33 years old, my partner Brandon was diagnosed with Glioblastoma Multiforme Grade 4 (GBM4), terminal Brain Cancer, on 1 May 2020 and died 10 months later on 10 March 2021, he was only 28 years old. Brandon and I have three children, our son is 11 and our identical twin daughters are 9. Our son was only 6 when Brandon died and our twin daughters just 4 years old. Brandon's diagnosis and prognosis hit us in the prime of our young lives, it shook us to our core and robbed us of everything we had hopes for as a family.

"Over the ten short months prior to Brandon's death, our family suffered not only the shock and pain of watching Brandon decline, but severe financial strain, repeated hospital stays, infections and surgeries, and the lasting trauma of unanswered questions, why, how, what can we do... nothing."

I write to share Brandon's story, continue to spread awareness for others and to call for sustained, targeted action, funding, support, from the Government so that maybe one day, other families don't have to face the same devastation that we have.

Brandon's Story

On 28 April 2020, Brandon left work for lunch and suddenly couldn't speak properly. At hospital, a CT scan revealed three brain masses, later confirmed by MRI. Within days, he underwent his first craniotomy.

On 30 April, surgery stretched from four hours to eight. Afterwards, Brandon struggled to communicate. The next day, we were told the devastating diagnosis - Glioblastoma Multiforme, Grade 4, the deadliest brain cancer. Prognosis: 12 months. Our world collapsed instantly.

"Brandon was discharged home. I left work to care for him full-time while raising our three children. Brandon could no longer work or drive, losing his independence and identity."

We survived on very limited Centrelink payments that barely covered living costs. He began radiation and chemotherapy, though COVID restrictions meant he could often only have 1 support person.

Soon after, Brandon suffered a seizure when I was driving. A new tumour was found, leading to a second craniotomy on 12 August. He woke with paralysis on his right side, mainly his leg, but was determined to walk again, refusing a wheelchair. Weeks later, an infection forced the removal of his bone flap from his skull, which changed the shape of his head.

"He endured multiple surgeries, daily hospital visits for antibiotics, and more delays to treatment. Eventually, scans showed the cancer had grown despite everything."

Doctors offered second-line chemotherapy, but quality of life versus quantity became the central question. Brandon chose to keep fighting. The following months were brutal, seizures, confusion, anger, loss of mobility, vision, and appetite. The children witnessed his decline, and I answered their questions with honesty. Palliative care became involved, but Glioblastoma stripped away dignity and independence.

By February 2021, the cancer had spread aggressively throughout his brain. Brandon, once so vibrant, could no longer move without assistance. Both rounds of chemo had failed. His doctors admitted how unusually aggressive his case was, especially for his age.

“On 10 February, Brandon declined rapidly and was transferred to Clare Holland House. Surrounded by love, drawings from the kids, and small comforts, he gave us one last gift - managing to say “I love you.”

On 10 March 2021, just 10 months after diagnosis, Brandon died. The children and I were by his side.

“The emotional, financial, and psychological impacts will remain with us forever, but so too does the resilience, love, and support of our family and community that carried us through the darkest of times.”

What We Need

Brain cancer kills more children and adults under 40 in Australia than any other cancer, yet receives only a fraction of research funding. Families are left devastated while progress stalls. I am calling on the government to:

- **Increase targeted funding for** Glioblastoma research.
- **Support clinical trials** to give patients access to new treatments.
- **Improve financial support** for families suddenly forced into full-time caring roles and support after the fact.
- **Expand palliative care**, with services that recognise the unique needs of young adults. Clare Holland House provided incredible care and support, for which we are forever grateful. However, it was the only option available for Brandon, and not designed for young people.

At 28, being the youngest patient was very difficult for him, highlighting how isolating palliative care can be for younger patients. There were no peers his age and no relatable environment, showing the clear need for age-appropriate palliative care where young patients and their families feel understood and supported.

There are many families like ours who will never understand why Glioblastoma took someone from them, the patient never gets answers either. This adds a different type of grief to the picture and leaves families anxious and confused, with all of their questions left unanswered. GBM has no known cause, no clear risk factors, lifestyle links, we don't know if it is genetic or not, there are no definitive answers. Patients face this reality alone, and families and loved ones are left asking questions that science cannot yet answer. This is why more research is essential - How to treat it better, extend life meaningfully, and one day find a cure.

“Families and communities need hope, and we all deserve answers - more awareness needs to be circulated, more action taken.”

Brandon’s bravery, humour, determination and love will never be forgotten. We will continue advocating for Brandon, for awareness, funding, and the supports that families need.

“Please act now - For Brandon, for our children, and for all families and loved ones facing Brain Cancer.”

Shae Jones –

Brandon’s Partner

Australia’s brain cancer stakeholder ecosystem

Where we have come from: A fragmented sector driven by the devastating impact of brain cancer

Due to the devastating impact of brain cancer on patients and their families, and the lack of dedicated support available for those navigating this disease, patients and families are left with significant unmet needs. Historically, this has driven affected individuals, families, clinicians, and researchers to establish initiatives to progress research towards improving outcomes, fill gaps in care and support in the ecosystem, and help advocate for the sector.

Case Study: Clinicians uniting against the disparity of funding and awareness for brain cancer [71]

In 2000, the Brain Cancer Group was formed by neurosurgeons Dr Raymond Cook and Dr Michael Biggs, and joined by medical oncologist Dr Helen Wheeler united by a common awareness that brain cancer patients lack the support, funding, and awareness in comparison to other cancer types.

The Group is committed to improving the care and outcomes for patients, through enhancing brain tumour research, education, and patients and carer support.

By leveraging their clinical expertise, The Brain Cancer Group pioneers preclinical and clinical research, drive awareness and education for healthcare professionals, and support brain cancer patients navigate the journey with a dedicated nurse practitioner.

Case Study: Advancing research to end paediatric brain cancer, and supporting patients in the meantime [72]

Driven by the deeply personal experience of losing her son Robert ‘Connor’ Dawes after a 16-month battle with paediatric brain cancer in 2013, Liz Dawes, was inspired to found the Robert Connor Dawes Foundation to build on his legacy. The Foundation provides significant funding for advancing paediatric brain cancer research across Australia and the USA, with the aim to significantly improve outcomes. In addition to funding for research and clinical trials, the Robert Connor Dawes Foundation supports patients and families through rehabilitation therapies, such as music therapy, providing comfort to patients, and supports awareness and growth of brain cancer practitioners and researchers through travel grants to attend national and international conferences.

As a result of the poor prognosis and outcomes for brain cancer, a core focus for many organisations is to fund and support research into developing new treatments and improve outcomes. Supplementary to this, foundations driven through personal experiences may also provide and fund support services to patients and families based on their own journey, and the gaps in clinical care and support services experienced in the Australian landscape.

The organisations can be categorised into three pillars, integral to supporting and improving the outcomes and lived experience of individuals and families affected by brain cancer.

Research & Clinical Trials

- Organisations driving discovery and innovation through laboratory research, translational science and clinical trials.

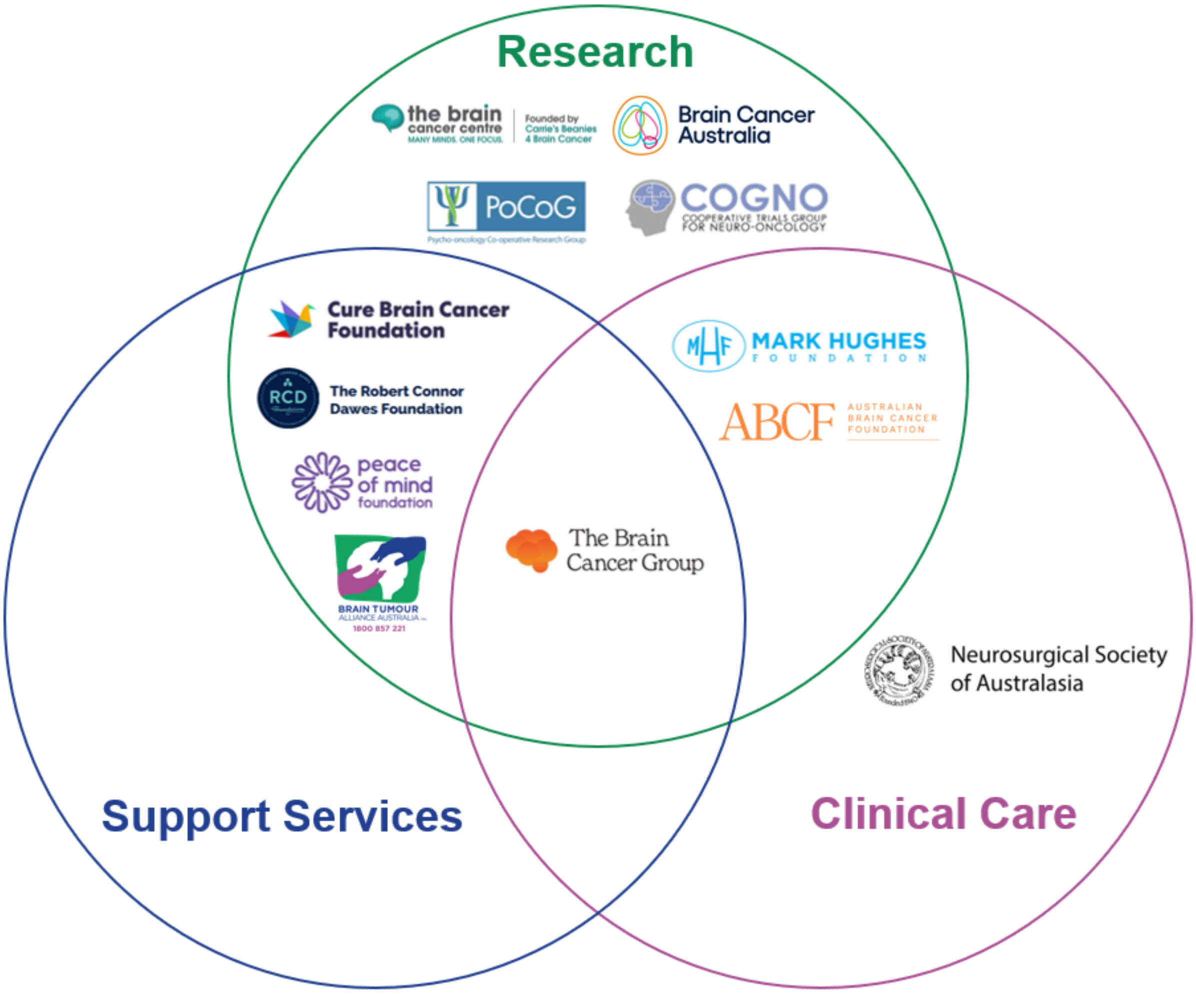
Clinical Care

- Organisations delivering multidisciplinary, patient-centred care across neurosurgery, oncology, rehabilitation and palliative care.

Support Services

- Organisations providing psychosocial, financial and practical support for patients, families and carers, to improve quality of life beyond the clinical setting.

Figure 7: Landscape of Brain Cancer Stakeholders and their place in supporting the ecosystem



The array of organisations seeking to support patients and families provide invaluable services and support, however, also create a fragmented and in some cases inequitable landscape of resources, such as in the availability of BCCCs which are funded in certain regions by patient advocacy organisations.

Uniting the landscape of experiences and organisations is the acute awareness of the need and motivation to advocate for continued research, and support patients and families. This advocacy occurs on an individual level, however despite these individual efforts, the absence of sustained government focus and adequate national coordination has emphasised the necessity for greater collaboration and the establishment of a cohesive national voice – such as the ABTC – to unify and amplify their impact.

The current brain cancer ecosystem: Unification and collaboration driven by shared goals to improve brain cancer outcomes

The Power of United Action: The Australian Brain Tumour Collaborative (ABTC)

Recognising the power of collective action, the ABTC was established to unite the diverse network of brain cancer foundations under a single banner, fostering collaboration and amplifying their shared commitment to improving outcomes for all Australians affected by brain cancer.

Origins and purpose: The ABTC unites Australia's brain cancer foundations

The ABTC was born from a discussion in October 2021 between the BTAA Chair and Committee and then Shadow Minister for Health, Mark Butler.

BTAA sought advice on how to raise government awareness of the dire impacts of brain tumours and ensure an appropriate national response. Mr Butler highlighted a major challenge: governments struggle to act when multiple consumer stakeholders approach the same problem from different perspectives. He recommended that, wherever possible, the brain tumour community should collaborate to provide a single united voice to government, offering a clear and coordinated understanding of the issues and solutions.

In response, BTAA initiated and funded the establishment of the ABTC which was formally launched in December 2022.

The Collaborative's purpose is to:

- Unite Australia's brain tumour sector under one collaborative framework
- Align and integrate fragmented efforts across research, clinical care, and consumer support
- Amplify the lived experience voice to inform research, care and policy
- Drive national-scale action to improve outcomes and equity

Membership and Governance: The ABTC is comprised of nine leading national organisations spanning the full brain tumour journey, from research to care

The ABTC's steering committee includes nine major national brain cancer foundations and organisations representing the full spectrum of the brain tumour journey — from laboratory research to end-of-life care, from clinical trials to psychosocial support:

- Brain Tumour Alliance Australia (BTAA)
- Mark Hughes Foundation
- Robert Connor Dawes Foundation
- Peace of Mind Foundation

- The Brain Cancer Group
- Cure Brain Cancer Foundation
- The Brain Cancer Centre
- Cooperative Trials Group for Neuro-Oncology (COGNO)
- Psycho-Oncology Co-operative Research Group (PoCoG)

The ABTC operates through a formal Steering Committee with Terms of Reference and a clear governance structure. A core theme is that while the ABTC presents a united national voice, each member organisation retains its independence and vital connections to its community.

The sheer number of national foundations involved - despite brain cancer being classified as a low-incidence cancer - reflects the complexity, diversity, and severity of brain cancer and its impacts.

Core Objectives: The ABTC drives collaboration, advocacy, and research to close critical gaps in brain tumour care, support, and treatment across the entire patient journey

1. Identify and promote understanding of key gaps in services and support for people impacted by brain tumours.
2. Promote integration, partnerships and information sharing within the national brain tumour sector that better supports people impacted by brain tumours.
3. Promote patient-centred solutions to challenges associated with the survivorship journey for people living with brain tumours, drawing on evidence-based research and lived experience.
4. Individually and collectively advocate for better access to service coordination and ongoing supports for people with brain tumours, their families, and carers.
5. Continue funding for research and clinical trials to enable and accelerate better prevention, treatments, and care.

These objectives underpin all three pillars of the Australian Brain Cancer Landscape: Research & Trials (Objective 5), Clinical Care (Objectives 1, 3, 4), and Supports (Objectives 1, 2, 3, 4).

Demonstrated Impact: The ABTC has unified the sector to drive national advocacy, data-informed care, and coordinated action across research, support and clinical services

Since its establishment, the ABTC has:

- Advocated for a national brain cancer research and trials roadmap
- Led national advocacy to secure government support for: a dedicated Brain Cancer Care Coordinator (BCCC) workforce, and the National Brain Cancer Advocacy Service (NAS)
- Consolidated data from programs such as BRAINS to inform clinical care and survivorship models
- Brought unprecedented collaboration between formerly siloed research, support and clinical organisations
- Presented a unified consumer voice to federal government

NDIS Priority Pathway

In late 2023, the NDIS implemented an undeclared policy that restricted brain tumour patients' access on the basis that they were generally palliative (and thus a State responsibility).

ABTC led a nine-month national engagement effort with the Australian Government, partnering with NAS to present evidence and lived experience data on survivorship needs. This resulted in the reversal of the policy and the creation of a government-initiated priority pathway for brain cancer patients meeting access criteria — which remains in place, with NAS actively engaged and supporting departmental teams.

Advocacy for Dedicated BCCCs

In 2023, the government announced the ACNNP to improve navigation support for all cancer patients. Despite more than 14 years of lobbying, brain cancer was not allocated dedicated funding or nurses within the ACNNP model.

The ABTC has since:

- Led engagement with government including the Department of Health and Aged Care to address this oversight
- Initiated and funded the landmark report 'Navigating the Unknown – A Call for Nationwide Brain Cancer Coordination'
- Submitted a 2025 pre-budget proposal calling for a National BCCC Framework

This advocacy continues, with ABTC providing a unified national platform for ongoing government engagement on this critical gap.

Strategic Role in the Three Pillars: The ABTC has an important role in supporting the three core pillars

Pillar	How ABTC Strengthens It
Research & Trials	Aligns research with lived experience, advocates for national roadmaps, reduces duplication, drives shared knowledge and awareness and trial capacity.
Clinical Care	Promotes integration and standardisation of care, supports BCCC framework, embeds survivorship evidence and data (e.g. from the BRAINS Program).
Support Services	Connects consumer-led organisations, aligns advocacy strategies, and links peer support and navigation services with clinical and research networks through the NAS.

To realise its full potential, the ABTC seeks:

- Formal government recognition and support as a national voice for the brain tumour sector
- Sustained funding for collaborative infrastructure, consumer engagement, and data-sharing systems
- Inclusion in the governance of ABCM 2.0, the National Brain Cancer Research & Trials Roadmap, and reforms in Clinical Care and Supports

The ABTC embodies the principle that collective action achieves what no single organisation can.

By uniting Australia’s leading brain tumour organisations, the ABTC is building the environment needed to transform outcomes, delivering better research, more equitable care, stronger supports, and a more powerful voice for Australians living with brain tumours.

Advocacy and awareness

Raising awareness and driving advocacy efforts are crucial in the fight against brain cancer. Despite the profound impact on individuals and families, brain cancer has not received the attention or resources needed to accelerate progress. By amplifying community voices and championing change at the highest levels, advocacy becomes the catalyst for greater investment, collaborative research, and the development of more effective care and support services for all Australians affected by brain cancer.

Recent advocacy efforts: Elevating the voices of Australians with brain cancer

Head to the Hill: Connecting the brain cancer community to government

Origins of the initiative

In 2023, BTAA launched Head to the Hill, the first national brain cancer advocacy event held at Parliament House in Canberra. Inspired by similar initiatives overseas, the event was designed to bring patients, carers, families, clinicians, and researchers directly into conversation with federal policymakers.

For decades, brain cancer had been described as a forgotten or rare cancer. Patients and families carried devastating burdens, but their voices were largely absent from the national stage. Head to the Hill was created to change that - providing a platform for lived experience stories to shape political and health policy discussions.

What makes head to the hill unique?

- **Lived experience at the centre:** Families and survivors travel from across the country to share their personal journeys with MPs and Senators.
- **United advocacy:** The event is led by BTAA as the peak national advocacy body, and supported by the ABTC, bringing nine major foundations together on shared priorities.
- **Evidence + emotion:** Policy papers, burden-of-disease data, and cost analyses are presented alongside powerful testimonies from patients and carers. This mix makes the message both rationally compelling and emotionally undeniable.
- **Parliamentary engagement:** Meetings are held with Ministers, Shadow Ministers, and crossbench MPs. Politicians hear directly how brain cancer impacts constituents in every electorate.

Highlights to date

- The inaugural event in November 2023 brought together patients, carers, clinicians, and nine foundations — the largest national gathering for brain cancer ever held in Parliament House.
- Media coverage amplified the call for recognition, with stories of families featured in major outlets.
- Direct engagement with Ministers and senior officials put brain cancer on the national policy agenda in a way not seen before.

- The 2024 event built on this momentum, uniting over a hundred advocates in Canberra.

Outcomes and impact

Since its inception, Head to the Hill has:

- Raised national awareness of the devastating impact of brain cancer.
- Informed government's understanding of the complex needs of patients and families.
- Helped secure meetings and progress on:
  - Development of a National BCCC Framework.
  - Support for the NAS.
  - Discussion of a reset of the ABCM 2.0.

Most importantly, Head to the Hill has given patients and families a direct sense of empowerment - that their voices matter, and that their experiences can influence change at the highest levels of government.

The future of Head to the Hill

BTAA have committed to cement Head to the Hill as the flagship national advocacy event for the brain cancer community. Each year, this event will bring patients, carers, clinicians and researchers together to focus government attention on the needs of the brain cancer community.

The event will focus on bringing a united national voice to government, driving policy and funding commitments, following up on actions from previous years, and aligning advocacy efforts with national cancer and health strategies.

By combining lived experience with data and policy evidence, it will improve decision-makers awareness and understanding of both the human and system impacts of brain cancer, ensuring it remains visible on the federal health agenda.

Current strengths and opportunities in the sector across the three core pillars

Brain cancer research and clinical trials in Australia

A pivotal step in improving outcomes for brain cancer patients: The Australian Brain Cancer Mission

With outcomes in brain cancer devastatingly poor, and a lack of beneficial treatment options available as standard of care, progressing research towards innovative treatments and ensuring patients have access to clinical trials is critical to improving outcomes.

In 2018, the Commonwealth Government launched the ABCM – a landmark investment of $133.66 million, comprising $60.26 million from the Australian Government, and $70.4 million from funding partners to support research into brain cancer over a 10-year period [9], [73]. This brought a significant and stepwise increase in brain cancer research funding up from approximately $20 million between 2015-2017, and allowed the funding of over 161 research projects [73]. The original aims of the ABCM were to [73]:

- Double the survival rate of Australians living with brain cancer over 10 years;
- Improve quality of life for people with brain cancer;
- Give all adult and child patients with brain cancer a chance to join a clinical trial;
- Boost Australian research and build research capacity.

Since 2018, the ABCM has been transformative in delivering critical system and capacity gains, necessary for significant change in brain cancer outcomes. An independent review showed the successes achieved by the ABCM [73].

The Australian Brain Cancer Mission has delivered critical successes, including:

Increased funding for brain cancer research through partnerships

First large-scale, co-funded mission between government and philanthropy- attracting additional funding and laying the foundations to bridge critical funding gaps in the landscape.

Expanded access to clinical trials

Funded 17 projects through the MRFF, which provided access to more than 1,350 patients, and is expected to support 70 new trial sites, and participation of more than 1,600 patients in clinical trials over the next 5 years.

Strengthened research and translational capacity

Increased the brain cancer workforce capacity by attracting researchers from other areas, funded shared infrastructure such as biobanks and data platforms, and strengthened the peak bodies, ANZCHOG and COGNO, which coordinate and administer clinical trials.

Progressed survivorship research

Addressed a critical funding gap, with 44% of funding put towards survivorship, building an understanding of long-term quality of life and functional impacts.

The Australian brain cancer research landscape: Strong foundations poised for growth and success

The brain cancer research landscape is underpinned by several core collaborative groups, which coordinate and bring together networks of scientists and clinicians focused and set up to coordinate research and trials in brain cancer.

The Australian Brain Cancer Research Alliance (ABCARA)

Founded in 2021, the ABCARA is an alliance of brain cancer focused clinicians, researchers, and clinician scientists with a long-term interest in adult brain cancer research [74]. The alliance serves as a critical partnership delivering multidisciplinary research projects and facilitating knowledge sharing, collaboration, and alignment of research priorities [74]. ABCARA has eight core research projects led by leading researchers and clinicians across Australia that cut across various dimensions of brain cancer with the aim of extending and improving the lives of brain cancer patients. These research projects are 1) Artificial Intelligence, 2) Biomarkers, 3) Tumour Heterogeneity, 4) Imaging, 5) Immunology, 6) Radiation, 7) Genetic Models, and 8) Drug Discovery [74]. Harnessing the collective expertise of MDTs, spanning both research and clinical practice, will help truly drive transformative progress in brain cancer outcomes, far beyond incremental improvements.

The Cancer Australia Cancer Cooperative Trials Groups – Cooperative Trials Groups for Neuro-Oncology (COGNO), and Australian and New Zealand Children's Haematology and Oncology Group (ANZCHOG)

These two groups were established prior to the ABCM with the aim of supporting research and clinical trials for adult brain cancer and children with cancer respectively. A core aim of the mission was to expand and enhance the capacity of these existing groups to support access to clinical trials in Australia [73]. Through the ABCM, these networks have successfully been uplifted to being reputable trials groups on the international stage, positioned to bring and lead new clinical trials for Australian patients [73]. In addition to their critical role in clinical trial access, these groups also support broader scientific research, including support for local and national biobanking efforts including that led by Brain Cancer Australia, which aims to provide and coordinate access to tissue samples and data across Australia, and ANZCHOG contributing to digital data sharing and platforms, and filling other research gaps [73].

Psycho-oncology Cooperative Research Group (PoCoG)

PoCoG is a multi-disciplinary group of healthcare professionals and researchers with a mission aimed at improving the emotional support and psychological and survivorship care of all people affected by cancer [75]. They are a Cancer Australia funded Cancer Cooperative Trial Group, similar to COGNO and ANZCHOG, working broadly across all cancer types. Given the high burden of disease, and long-term impacts of brain cancer survivors, PoCoG is a critical element of the overall brain cancer research and trials landscape. PoCoG led the ABCF-funded BRAINS Program and continues to lead supportive and psychological care trials in brain cancer.

In addition to these strong collaborative networks, several dedicated research centres have also been established, concentrating scientists together, all working on the challenge of brain cancer.

The Mark Hughes Foundation Centre for Brain Cancer Research

Formed as a partnership between the Mark Hughes Foundation, and the University of Newcastle, the centre has more than 40 employees, including more than 20 post-doctoral researchers and PhD students, committed to pioneering research in brain cancer. The Centre has six dedicated research streams: 1) Patient Experience, 2) Brain Cancer Imaging, 3) Experimental Therapeutics, 4) Blood Based Biomarkers, 5) Translational Neuroscience, and 6) Paediatric Brain Cancer.

The Brain Cancer Centre

The Brain Cancer Centre was established through a partnership between Carrie's Beanies 4 Brain Cancer and the Walter and Eliza Hall Institute (WEHI), with support from the Victorian Government. The Centre now includes more than 90 researchers, and has 12 formal partnerships with hospitals, universities, and research institutes across Australia. The Centre currently has 14 research projects which span a range of disciplines from basic biology, novel diagnostic and therapeutic development, developing organoids and clinical models, and clinical trials [76].

The development of robust clinical networks, collaborative alliances, and dedicated research centres has established a strong foundation for brain cancer research in Australia, which has been further developed through the impact of recent investment and support. This foundation not only positions Australia to become a global leader and innovator in brain cancer research but also ensures that further investment will catalyse significant advancements, ultimately improving outcomes for patients facing this challenging disease. Continued commitment will be crucial to harness the momentum and address the high unmet needs within the brain cancer community.

Continuing a strong commitment to brain cancer research is crucial to building upon existing strengths and progressing innovative research

The ABCM was a landmark step that built foundations, partnerships, networks, and capacity, critical to enabling success in the challenge of brain cancer. While the initial investment represented a vital and much-needed commitment, laying the groundwork for significant progress, it's important to acknowledge that, like all cancer research, brain cancer remains an extraordinarily difficult challenge. Its complex biology means that breakthroughs cannot be achieved overnight; instead, ongoing focus and sustained, long-term support are essential to drive genuine improvements in outcomes.

The independent review of the ABCM identified several areas of remaining unmet need and areas for improvement. These include [73]:

- **Survivorship unchanged:** One of the core objectives of doubling survival remains unchanged.
- **Biology and discovery research underfunded**: Relatively less investment in basic research, at only 9% of projects (compared to 24% of international research projects), which is critical to delivering innovations that make more than incremental improvements and develop a pipeline of future clinical trials.
- **Under supported brain cancers:** Less funding towards adult brain cancer than paediatric cancer relative to the number of patients affected, and especially for glioblastoma, representing the largest burden.
- **Broader collaborations needed:** Leveraging the established networks, national groups and infrastructure to expand linkages with clinicians and industry is needed.
- **Workforce pressures:** Early-career and clinician-researchers need stronger support.
- **Conservative funding model:** The competitive grant system disincentivised innovative high-risk, high-reward research capable of delivering transformative change.
- **Inconsistent consumer engagement:** Further need to systematically engage with consumers, and embed their voice from design to delivery.
- **Lack of industry engagement and investment:** limited structural changes and incentives to provide a research and clinical trial landscape conducive to industry investment and partnership in low incidence cancers.

The Vision for the ABCM 2.0

Moving forward, subsequent investment into the ABCM will build on the strong established foundations and learnings to deliver breakthroughs and treatments that are less toxic and preserve quality of life, by:

- ✓ Being co-designed with government, philanthropy, researchers, clinicians, and the brain cancer community.
- ✓ Establishing a National Brain Cancer Research & Trials Roadmap with clear priorities and delivery horizons.
- ✓ Balancing basic science, clinical trials, and survivorship research to ensure a robust bench-to-bedside pipeline.
- ✓ Embedding the principles of the Australian Cancer Plan – equity, access, and ‘no one left behind’, as well as a specific focus on priority populations.
- ✓ Retaining and growing the brain cancer research workforce, including protecting clinician research time.
- ✓ Supporting high-risk, high-reward research to accelerate breakthroughs.
- ✓ Embedding a formal consumer engagement framework to ensure patient and care voices shape all investments.

The ask of Government

BTAA, with the support of the ABTC and the broader Australian brain cancer community call on the Australian Government to:

Research & Trials: Invest $200 million over 10 years to establish the Australian Brain Cancer Mission (ABCM) 2.0

Establish ABCM 2.0 as a renewed strategic partnership

Reset and renew the ABCM as ABCM 2.0, a co-designed partnership between government and philanthropic stakeholders. To enable

this, $200 million should be committed by government over a 10 year period. This would

be strengthened by additional philanthropic contributions.

This initiative will formalise shared governance, align strategic priorities, and secure sustainable funding to accelerate national efforts in brain cancer research, treatment and survivorship.

Build a national research and trials roadmap

Develop a comprehensive National Brain Cancer Research and Trials Roadmap that spans the full research continuum:

- Basic discovery science
- Translational research
- Clinical trials
- Survivorship and supportive care

This roadmap will guide coordinated investment, foster collaboration, and ensure measurable outcomes across all stages of brain cancer research.

Strengthen research enabling capabilities

Invest in the development of the workforce, infrastructure, data systems and collaborative networks that are needed to deliver scientific and clinical breakthroughs.

Research and clinical trials create the knowledge, treatments and innovations that clinical and supportive care teams can implement.

This investment and commitment by the Government will ensure the strong foundations of brain cancer research that have been built over the last few years are reinforced and built upon to deliver meaningful change in brain cancer outcomes for patients.

Pillar 2: Clinical Care

Brain Cancer Clinical Care in Australia

> *"For over a decade the community has been requesting government funding for [a national BCCC framework that will provide critical, much-needed support for Australian brain cancer patients and their families], dating back to 2011.*
>
> ***The exclusion of brain cancer from the Australian Cancer Nurse Navigator Program (ACNNP) has significantly impacted an already struggling community.***
>
> *Government and departmental representatives … have consistently acknowledged the unique, significant, and complex challenges of brain cancer. They have also noted that while brain cancer should ideally be funded through such programs, the current framework does not adequately address its complexities and a dedicated model for brain cancer is required.*
>
> ***Disappointingly, unlike many other cancers, the Australian brain cancer community has never received funding for survivorship supports****."*
>
> *– BTAA, extract from the BTAA budget submission*

Dedicated Brain Cancer Care Coordinators

BCCCs play a critical role in supporting patients and families through complex treatment pathways [77]. Despite evidence of their positive impact on clinical and economic outcomes, BCCC availability in Australia remains limited and unevenly distributed [78].

Coordinated care is essential for patients with brain cancer, who often experience neurocognitive impairment, psychosocial distress, and high symptom burden [29]. Care coordinators (typically nurses, social workers, neuropsychologists, or occupational therapists) facilitate multidisciplinary care, manage treatment-related complications, and provide psychosocial support [21]. Numerous studies have demonstrated that access to care coordination can reduce hospital length of stay, improve quality of life, and lower health system costs through reduced ED presentations and optimised resource utilisation [77], [79].

As of 2025, there are 29 BCCCs in Australia, representing 20.6 full-time equivalent positions [21]. This equates to one coordinator per 69 newly diagnosed patients, based on approximately 2,000 annual cases. Geographic distribution is highly centralised, with 90% of coordinators located in major cities on the east coast, while Western Australia and South Australia each have one coordinator, and Tasmania and the Northern Territory have none [21]. This maldistribution raises concerns about equitable access, particularly for regional and remote populations.

At least 25% of BCCC positions are funded wholly or partially by non-government organisations, indicating limited integration into core health service funding [21]. This reliance on philanthropic or non-profit support suggests systemic under-recognition of the role within cancer care policy frameworks. Recent advocacy efforts, including the ABTC 2025–26 pre-budget submission requesting $8.75 million for 23 additional positions, were unsuccessful [80], underscoring ongoing challenges in securing sustainable investment.

Limited and uneven access to BCCCs disproportionately affects patients in rural and remote areas, culturally and linguistically diverse communities, and Aboriginal and Torres Strait Islander peoples. These groups already experience barriers to care and may face additional challenges navigating the NDIS, where support costs for brain cancer patients are estimated to be four to five times higher than the national average [21]. Without targeted policy reform and dedicated funding, disparities in care coordination are likely to persist, with implications for patient outcomes and system efficiency.

BCCCs are integral to high-quality brain cancer care, yet current provision in Australia is inadequate and inequitable. Addressing workforce shortages and funding gaps should be a priority for health policy to ensure timely, coordinated, and patient-centred care for all Australians affected by brain cancer.

The Role of the Brain Cancer Care Coordinator

Implementation of the BCCC program in the Hunter New England Local Health District has delivered measurable cost savings and improved system efficiency for public hospitals [77]. Following the introduction of the BCCC intervention, some of the 187 enrolled glioblastoma patients aged ≥18 experienced a 24% reduction in total hospital length of stay and fewer ED presentations and admissions, without any negative impact on survival outcomes. The average cost per patient decreased by $1,200 for emergency visits and $5,500 for inpatient admissions, resulting in a total hospital saving exceeding $500,000 over a study period spanning approximately seven years (October 2012 and December 2019). These results provide robust economic justification for policymakers to support and expand care coordinator roles, as they optimise resource utilisation, reduce acute care demand, and maintain quality of care for patients with complex needs [77].

The national roll out of a BCCC program this year alone could have resulted in the avoidance of almost **2,700** ED presentations and over **11,000** inpatient days for glioblastoma patients, leading to a potential cost saving to the State of **$4.5 million** and **$21.4 million** respectively. With a national rollout in 2025, this would represent a total cost saving of **$25.9 million** to health budgets, nationally this year alone, not considering the cost of the intervention. With the projected increase in prevalence and healthcare costs for glioblastoma patients, this would climb to a system saving of **$60.8 million** annually in the year 2050: approximately **$11.3 million** for ED presentations and **$49.5 million** for inpatient days, not considering the BCCC service costs.

The national rollout of a BCCC service for glioblastoma patients would see approximately:

	Immediately	By 2050
Glioblastoma related ED presentations avoided	**2,700**	**6,300**
Healthcare cost savings	**$4.5m**	**$11.3m**
Reduction in length of stay (inpatient days)	**11,250**	**26,100**
Healthcare cost savings	**$21.4m**	**$49.5m**
Total savings	**$25.9m**	**$60.8m**

Source: Biointelect analysis [1]

Proposed framework for designated BCCCs

The brain cancer clinical care community has developed a proposed framework for designated BCCCs.

Feature	Key components
Role Scope	Designated BCCCs with specialist training (neuro-oncology allied health or nursing), embedded into disease/tumour-type clinics, with responsibility across the full disease trajectory, including: • Diagnosis • Treatment • Survivorship • Recurrence/palliative care • Bereavement
Core functions	Informed by the BRAINS Program and Delphi consensus and a roundtable held with BCCCs, the core functions would include: • Early needs assessment (patient & caregiver) • Regular screening (cognitive, functional, psychosocial symptoms) • Clinical system navigation and bridging across specialists, primary care, allied health, rehab • Clinical information & resource provision • Caregiver support interventions • Monitoring of clinical outcomes, including patient reported quality of life, distress, unplanned admissions, ED usage and caregiver burden.
Geographic & Access Equity	• Hub and satellite model: major metropolitan centres host coordinators; regional/rural areas supported with telehealth or outreach; ensure person-centred delivery across all regions. • Use BRAINS Program mapping data to identify where gaps are greatest
Integration & Governance	Coordinators operate within MDTs; integrate with national programs such as the ACNNP; Align with Optimal Care Pathways; national working group for standards, training, outcome measurement, and consumer engagement.
Funding & Scale	Phased rollout over three years, with $8-9 million funding over the period, to fund coordinators, operational costs, training and IT / data tools.

The ask of Government

BTAA with the support of all signatories on this document call on the Australian Government to:

Clinical Care: Invest $8.75 million to implement a national Brain Cancer Care Coordinator (BCCC) framework, including 23 specialised coordinators

National framework for coordinated care

Implement a national BCCC Framework, building upon the framework presented in this paper, to deliver consistent, end-to-end support for patients, from diagnosis through treatment, survivorship, recurrence and palliative care.

Embed coordinators in every care team

Embed BCCCs into multidisciplinary teams (MDTs) across metropolitan, regional and rural settings to ensure coordinated, equitable and patient-centred care nationwide.

Data driven deployment and outcomes

Leverage the BRAINS Program data to identify priority areas, direct resources to greatest need, and track measurable improvements in patient outcomes and service delivery.

Clinical care ensures every patient can access and benefit from best practice care and treatment, while reducing fragmentation and health system burden.

Pillar 3: Support Services

Brain cancer support services in Australia

Australians diagnosed with brain cancer face a critical gap in support

Unmet support needs despite high burden

Brain cancer patients and their families face the highest physical, cognitive, psychosocial and economic burden of any cancer with a five-year survival rate below 23%. Despite this, there is currently no government-funded, nationally coordinated support service dedicated to brain cancer patients and carers.

Sudden diagnosis and complex system navigation

Patients are often diagnosed with brain cancer suddenly, experiencing rapid deterioration and multiple service needs, but with no coordinated support to navigate complex health, disability and social systems. Parents of diagnosed children are also left without support to navigate the complex system whilst trying to make decisions for their affected child and juggle other children and work.

Fragmented and inequitable access to support

Current support is fragmented, underfunded, and metro-centric, leaving many people — especially those in regional, rural and remote communities — without any support at all. This creates significant inequities: some families receive comprehensive help, others are left to navigate alone while in crisis.

The National Advocacy Service: A proven national model that has supported more than 3,000 patients with brain cancer across Australia

The NAS is currently delivered by the Peace of Mind Foundation and was previously funded by the Cure Brain Cancer Foundation

The NAS is the only dedicated, national, consumer-led brain cancer support service in Australia. As a national support service, the NAS provides:

- Personalised support for patients, carers and families from diagnosis through survivorship, recurrence, palliative care and bereavement.
- Navigation and support through complex systems, including the NDIS, Centrelink, aged care, palliative care and mental health support.
- National reach, with phone, virtual and outreach support that explicitly targets regional, rural and remote communities where there are no local services.

- Linkage to clinical specialists, trials and medical advice.
- Peer support networks, connecting people with others who have lived experience.

The NAS ensures that people diagnosed with brain cancer, along with their carers and families, are not left to navigate the complex health system on their own. It provides personalised guidance and advocacy, helping them access the right services and support from the moment of diagnosis, no matter where they live in Australia.

> *The National Advocacy Service is completely invaluable to our U65 year old clients with brain tumours. We have had a number of clients successful in obtaining NDIS funding with the National Advocacy Service support. This is not something I can replicate in my role and it has profound impacts on the client and their carer being able to access greatly increased supports compared to the very minimal support we can access through palliative care.*
>
> - ***Palliative Care Occupational Therapist***

The importance of the NAS

National uptake of the NAS shows that it is a trusted service that is embedded in clinical care pathways. Since its launch in December 2021, the NAS has:

Supported ~3,000 patients and families across Australia

Projected to support a further 1,000 patients and families in 2025

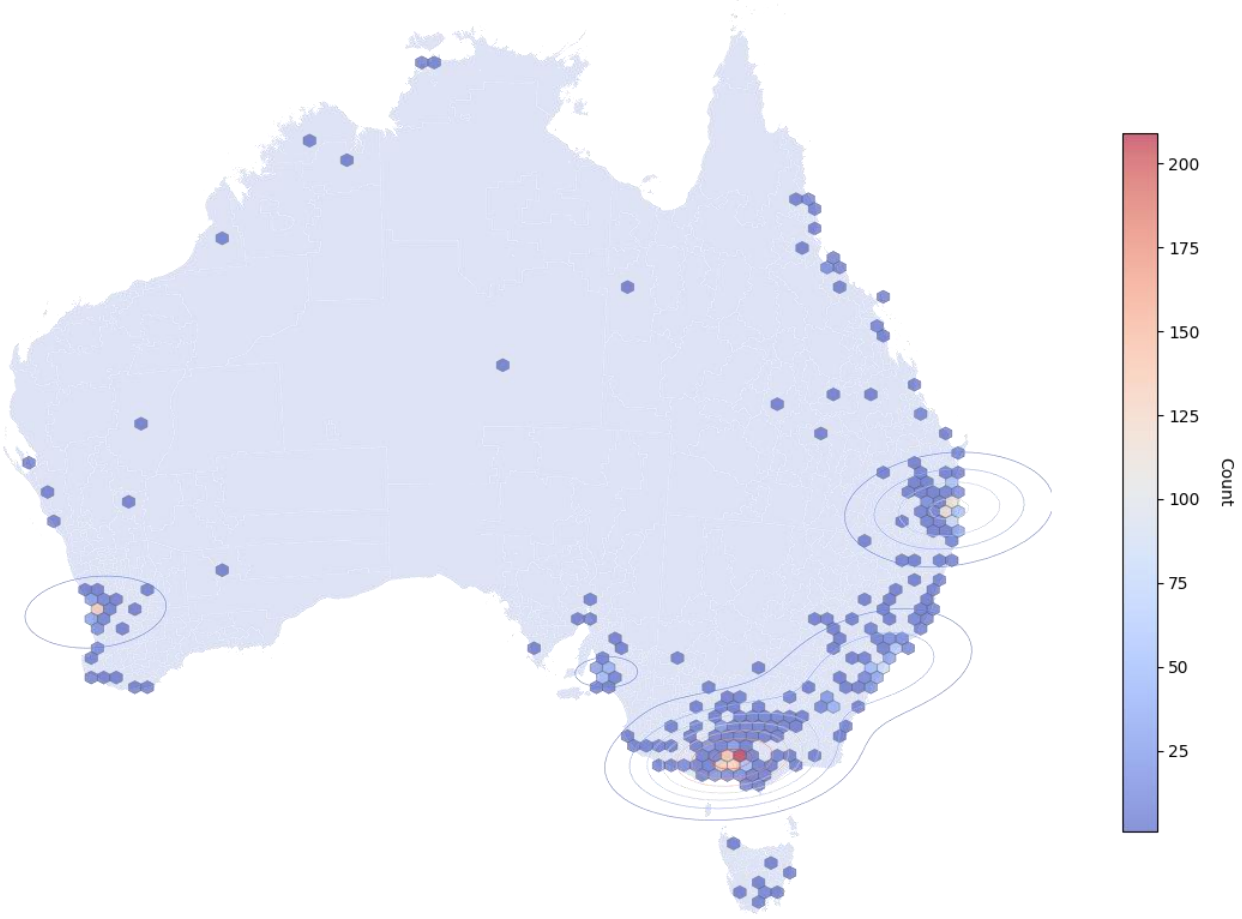
650+ referrers including clinicians and allied health professionals, across 180 hospitals and service providers

Alleviating health system burden and supporting equitable access

The NAS removes a significant burden from the health system, reducing pressure on hospital staff, clinics and administrators by handling non-clinical support needs. This relieves pressure on the health system by reducing duplication, delays and inappropriate ED and hospital use. In addition, the NAS supports equitable access by reaching regional, rural and remote communities and people from culturally and linguistically diverse backgrounds.

> *[Efficiencies gained include] decreased length of stay in hospital because people feel supported leaving, alleviating pressure on community and /out-patient services. - **Social Worker***

Figure 8: Regions in Australia supported by the NAS



Source of unique data collection

In addition to the support provided, the NAS collects data which has provided government with important and detailed insights into the patient and carer journey, particularly on the range and depth of disabilities and impairments caused by brain cancer and its treatments. Vitally, the data collected through the NAS is not collected elsewhere and provides valuable insights for the NDIS. These insights are shaping the government's understanding of the needs of patients and families and are being used to inform related services such as the current brain cancer nurse cohort.

The ask of Government

BTAA, with the support of Peace of Mind Foundation and all signatories on this document call on the Australian Government to:

Support Services: Sustain and scale the National Advocacy Service (NAS) with $1.175 million in dedicated annual funding

Sustain and scale the NAS

Secure and expand the NAS, delivered by Peace of Mind Foundation and currently funded by Cure Brain Cancer Foundation, to ensure continued support and greater impact.

Invest in workforce capacity

Provide dedicated funding for 8 FTE staff ($1.175M per year) to deliver tailored navigation, psychosocial support, and ensure equitable national reach.

Formalise the NAS as a peak national service

Recognise the NAS as a national peak consumer support service, fully integrated with BCCCs and aligned with national cancer navigation programs.

Support services provide the scaffolding families need to survive the journey and ensures lived experience informs research and care design.

In addition, as part of a Supports Roadmap the Australian Government should:

- Formally integrate NAS into the national cancer system with direct referral pathways from hospitals, MDTs, BCCCs and the ACNNP.
- Recognise the NAS as a national peak consumer support service for brain cancer, embedded within Cancer Australia’s consumer engagement framework.
- Support national evaluation and reporting on outcomes such as distress reduction, quality of life, service access, reach, and system cost savings.

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

The BRAINS Program was a $4.9 million Medical Research Future Fund (MRFF)-funded program from August 2020 to June 2025. The program of work aimed at delivering better survivorship and supportive care to people affected by brain cancer and their caregivers.

The program has improved our understanding of the frequency and severity of symptoms, as well as the care and survivorship needs of people with brain cancer across Australia. This knowledge has contributed to the development of more responsive, timely, and proportionate models of care coordination for patients and their caregivers.

Through five core pillars, the program has delivered an implementation-ready online portal to screen for unmet needs in people living with brain tumours, a screening portal for carers, an online resource to prepare caregivers for their role, detailed understanding of models of brain cancer care coordination, and development and evaluation of a series of psychosocial and supportive care interventions. Specifically:

- TeleMAST: telephone delivered psychotherapy using the ‘Making Sense of Brain Tumour’ program, providing people across Australia access to evidence-based psychological care.
- LaTCH-BRAINS: online delivery of a group memory intervention run for people with brain tumours, demonstrating improved memory experience and strategy use.
- RESTORE for brain tumours: developed an online intervention to increase ability to self-manage cancer and treatment related fatigue.
- Sleep disturbance: development of a stepped care approach to managing sleep disturbance in people with brain tumours.
- Recapture life: adaptation of an online program to support re-engagement with study and work amongst young people diagnosed with brain tumour (ages 14-40).

Additionally, the program has delivered foundational work on personality and behaviour changes experienced by people with brain tumours and its impacts on families. In addition, the program has delivered preliminary work to inform the development of communication skills training for healthcare professionals, to support communication with patients who have developed cognitive impairments.

The current challenge is to identify sustainable ways of making these interventions available to patients and families, and to fund research to evaluate newly developed interventions to ensure treatments offered are evidence-based.

A call to action: Co-designing a national strategy for brain cancer research and trials, clinical care and support services to improve brain cancer outcomes

In light of the profound health, social and economic burden of brain cancer revealed throughout this Landscape paper, it is imperative that national priorities are reflective of the true impact of this disease on Australians, their families and broader communities.

BTAA, with the support of all signatories, is calling on government to collaborate in co-designing a strategic roadmap that will drive tangible improvements and shape the future of research, clinical care and support for Australians living with and yet to be diagnosed with brain cancer.

Research and trials, clinical care and support are all interconnected. Change is therefore needed across all three pillars, to make meaningful advancements in brain cancer.

Recommendations to Government

As described throughout this paper, BTAA and the ABTC have worked collaboratively to develop three priority actions, to make progress in brain cancer outcomes.

Research & Trials: Invest $200 million over 10 years to establish the Australian Brain Cancer Mission (ABCM) 2.0

Establish ABCM 2.0 as a renewed strategic partnership

Reset and renew the ABCM as ABCM 2.0, a co-designed partnership between government and philanthropic stakeholders. To enable this, $200 million should be committed by government over a 10 year period. This would be strengthened by additional philanthropic contributions.

This initiative will formalise shared governance, align strategic priorities, and secure sustainable funding to accelerate national efforts in brain cancer research, treatment and survivorship.

Build a national research and trials roadmap

Develop a comprehensive National Brain Cancer Research and Trials Roadmap that spans the full research continuum:

- Basic discovery science
- Translational research
- Clinical trials
- Survivorship and supportive care

This roadmap will guide coordinated investment, foster collaboration, and ensure measurable outcomes across all stages of brain cancer research.

Strengthen research enabling capabilities

Invest in the development of the workforce, infrastructure, data systems and collaborative networks that are needed to deliver scientific and clinical breakthroughs.

Research and clinical trials create the knowledge, treatments and innovations that clinical and supportive care teams can implement.

Clinical Care: Invest $8.75 million to implement a national Brain Cancer Care Coordinator (BCCC) framework, including 23 specialised coordinators

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Appendices

References

[1] "Biointelect analysis," 2025.

[2] Australian Institute of Health and Welfare, "Overview of cancer in Australia, 2024," Australian Institute of Health and Welfare. Accessed: Sept. 25, 2025. [Online]. Available: https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/overview

[3] D. N. Louis *et al.*, "The 2021 WHO Classification of Tumors of the Central Nervous System: a summary," *Neuro-Oncol.*, vol. 23, no. 8, pp. 1231–1251, June 2021, doi: 10.1093/neuonc/noab106.

[4] "Brain Tumor Types." Accessed: Sept. 25, 2025. [Online]. Available: https://www.hopkinsmedicine.org/health/conditions-and-diseases/brain-tumor/brain-tumor-types

[5] Cancer Australia, "Brain cancer in Australia statistics." Accessed: Sept. 25, 2025. [Online]. Available: https://www.canceraustralia.gov.au/cancer-types/brain-cancer/brain-cancer-australia-statistics

[6] Australian Institute of Health and Welfare, "Cancer data in Australia," Australian Institute of Health and Welfare. Accessed: Sept. 25, 2025. [Online]. Available: https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/about

[7] "Introduction | Financial Cost of Cancer | Treatment and Care Policy." Accessed: Sept. 26, 2025. [Online]. Available: https://www.cancer.org.au/about-us/policy-and-advocacy/treatment-care/financial-cost-of-cancer/introduction

[8] "Rural and remote health," Australian Institute of Health and Welfare. Accessed: Sept. 25, 2025. [Online]. Available: https://www.aihw.gov.au/reports/rural-remote-australians/rural-and-remote-health

[9] Australian Government, "Australian Brain Cancer Mission," Department of Health, Disability and Ageing. Accessed: Sept. 25, 2025. [Online]. Available: https://www.health.gov.au/our-work/mrff-australian-brain-cancer-mission

[10] R. Stupp *et al.*, "Effects of radiotherapy with concomitant and adjuvant temozolomide versus radiotherapy alone on survival in glioblastoma in a randomised phase III study: 5-year analysis of the EORTC-NCIC trial," *Lancet Oncol.*, vol. 10, no. 5, pp. 459–466, May 2009, doi: 10.1016/S1470-2045(09)70025-7.

[11] M. Weller *et al.*, "European Association for Neuro-Oncology (EANO) guideline on the diagnosis and treatment of adult astrocytic and oligodendroglial gliomas," *Lancet Oncol.*, vol. 18, no. 6, pp. e315–e329, June 2017, doi: 10.1016/S1470-2045(17)30194-8.

[12] S. Rogers *et al.*, "Re-irradiation for recurrent glioblastoma: a pattern of care analysis," *BMC Neurol.*, vol. 24, no. 1, p. 462, Nov. 2024, doi: 10.1186/s12883-024-03954-z.

[13] R. S. Angom, N. M. R. Nakka, and S. Bhattacharya, "Advances in Glioblastoma Therapy: An Update on Current Approaches," *Brain Sci.*, vol. 13, no. 11, p. 1536, Oct. 2023, doi: 10.3390/brainsci13111536.

[14] M. Weller, T. Cloughesy, J. R. Perry, and W. Wick, "Standards of care for treatment of recurrent glioblastoma—are we there yet?," *Neuro-Oncol.*, vol. 15, no. 1, pp. 4–27, Jan. 2013, doi: 10.1093/neuonc/nos273.

[15] A. A. Brandes *et al.*, "Recurrence Pattern After Temozolomide Concomitant With and Adjuvant to Radiotherapy in Newly Diagnosed Patients With Glioblastoma: Correlation With MGMT Promoter Methylation Status," *J. Clin. Oncol.*, vol. 27, no. 8, pp. 1275–1279, Mar. 2009, doi: 10.1200/JCO.2008.19.4969.

[16] "Pediatric brain tumors - Symptoms and causes," Mayo Clinic. Accessed: Sept. 25, 2025. [Online]. Available: https://www.mayoclinic.org/diseases-conditions/pediatric-brain-tumor/symptoms-causes/syc-20361694

[17] “Types of Brain and Spinal Cord Tumors in Children.” Accessed: Sept. 25, 2025. [Online]. Available: https://www.cancer.org/cancer/types/brain-spinal-cord-tumors-children/about/types-of-brain-and-spinal-tumors.html

[18] “What are the different types of brain tumours in children?” Accessed: Sept. 26, 2025. [Online]. Available: https://www.cancerresearchuk.org/about-cancer/childrens-cancer/brain-tumours/types/different-types

[19] S. R. Kesler, C. Sleurs, B. C. McDonald, S. Deprez, E. van der Plas, and B. J. Nieman, “Brain Imaging in Pediatric Cancer Survivors: Correlates of Cognitive Impairment,” *J. Clin. Oncol.*, vol. 39, no. 16, pp. 1775–1785, June 2021, doi: 10.1200/JCO.20.02315.

[20] “Brain Tumors,” AANS. Accessed: Sept. 26, 2025. [Online]. Available: https://www.aans.org/patients/conditions-treatments/brain-tumors/

[21] Evohealth, “Navigating the unknown: A call for nationwide brain cancer care coordination,” 2024. [Online]. Available: https://www.evohealth.com.au/wp-content/uploads/2025/06/Navigating_the_Unknown.pdf

[22] M. Zhao, Y. Liu, G. Ding, D. Qu, and H. Qu, “Online database for brain cancer-implicated genes: exploring the subtype-specific mechanisms of brain cancer,” *BMC Genomics*, vol. 22, no. 1, p. 458, June 2021, doi: 10.1186/s12864-021-07793-x.

[23] “Genetic Testing Fact Sheet - NCI.” Accessed: Sept. 25, 2025. [Online]. Available: https://www.cancer.gov/about-cancer/causes-prevention/genetics/genetic-testing-fact-sheet

[24] Y. H. Byun and C.-K. Park, “Classification and Diagnosis of Adult Glioma: A Scoping Review,” *Brain Neurorehabilitation*, vol. 15, no. 3, Nov. 2022, doi: 10.12786/bn.2022.15.e23.

[25] “New genetic test could diagnose brain tumours in as little as two hour,” Brain Tumour Research. Accessed: Sept. 25, 2025. [Online]. Available: https://braintumourresearch.org/blogs/latest-news/new-genetic-test-could-diagnose-brain-tumours-in-as-little-as-two-hours

[26] K. Conger, “Genes linked to familial brain cancer identified in Stanford Medicine-led study,” News Center. Accessed: Sept. 25, 2025. [Online]. Available: https://med.stanford.edu/news/all-news/2023/05/familial-brain-cancer.html

[27] M. S. A. Committee, “Somatic gene testing for the diagnosis of glioma, including glioblastoma.” Accessed: Sept. 25, 2025. [Online]. Available: https://www.msac.gov.au/applications/1709

[28] Cancer Council, “Understanding Changes in Thinking and Memory,” 2023. [Online]. Available: https://www.cancer.org.au/assets/pdf/changes-in-thinking-and-memory

[29] M. Pertz, U. Schlegel, and P. Thoma, “Sociocognitive Functioning and Psychosocial Burden in Patients with Brain Tumors,” *Cancers*, vol. 14, no. 3, p. 767, Jan. 2022, doi: 10.3390/cancers14030767.

[30] G.-C. Moroşan, A.-C. Moroşan, C. Ionescu, and A. Sava, “Neuropsychiatric symptoms as early indicators of brain tumors,” *Arch. Clin. Cases*, vol. 11, no. 4, pp. 120–126, Dec. 2024, doi: 10.22551/2024.45.1104.10302.

[31] R. R. Samman *et al.*, “The Impact of Brain Tumors on Emotional and Behavioral Functioning,” *Cureus*, vol. 16, no. 12, p. e75315, doi: 10.7759/cureus.75315.

[32] “Your health care team,” Cancer Council NSW. Accessed: Oct. 08, 2025. [Online]. Available: https://www.cancercouncil.com.au/brain-cancer/diagnosis/health-professionals/

[33] M. O’Connor, K. White, L. J. Kristjanson, K. Cousins, and L. Wilkes, “The prevalence of anxiety and depression in palliative care patients with cancer in Western Australia and New South Wales,” *Med. J. Aust.*, vol. 193, no. S5, pp. S44–S47, 2010, doi: 10.5694/j.1326-5377.2010.tb03927.x.

[34] K. M. Lion *et al.*, “Access to psychosocial support for people with brain tumor and family members: Healthcare professional perspectives,” *Psychooncology.*, vol. 32, no. 6, pp. 980–988, 2023, doi: 10.1002/pon.6142.

[35] G. K. B. Halkett *et al.*, “Distress and psychological morbidity do not reduce over time in carers of patients with high-grade glioma,” *Support. Care Cancer*, vol. 25, no. 3, pp. 887–893, Mar. 2017, doi: 10.1007/s00520-016-3478-6.
[36] A. Rodríguez-Prat *et al.*, “The Wish to Hasten Death in Patients With Life-Limiting Conditions. A Systematic Overview,” *J. Pain Symptom Manage.*, vol. 68, no. 2, pp. e91–e115, Aug. 2024, doi: 10.1016/j.jpainsymman.2024.04.023.
[37] H. Haroen *et al.*, “The benefits of early palliative care on psychological well-being, functional status, and health-related quality of life among cancer patients and their caregivers: a systematic review and meta-analysis,” *BMC Palliat. Care*, vol. 24, no. 1, p. 120, Apr. 2025, doi: 10.1186/s12904-025-01737-y.
[38] Mark Hughes Foundation, “About Brain Cancer.” Accessed: Sept. 25, 2025. [Online]. Available: https://markhughesfoundation.com.au/about/brain-cancer/
[39] “How brain tumours are graded,” The Brain Tumour Charity. Accessed: Sept. 26, 2025. [Online]. Available: https://www.thebraintumourcharity.org/brain-tumour-diagnosis-treatment/how-brain-tumours-are-diagnosed/how-brain-tumours-are-graded/
[40] T. Ajithkumar *et al.*, “Uncommon low-grade brain tumors,” *Neuro-Oncol.*, vol. 21, no. 2, pp. 151–166, Feb. 2019, doi: 10.1093/neuonc/noy151.
[41] M. A. Vaz-Salgado *et al.*, “Recurrent Glioblastoma: A Review of the Treatment Options,” *Cancers*, vol. 15, no. 17, p. 4279, Aug. 2023, doi: 10.3390/cancers15174279.
[42] Cancer Australia, “Prostate cancer in Australia statistics.” Accessed: Sept. 26, 2025. [Online]. Available: https://www.canceraustralia.gov.au/cancer-types/prostate-cancer/prostate-cancer-australia-statistics
[43] Cancer Australia, “Breast cancer in Australia statistics.” Accessed: Sept. 26, 2025. [Online]. Available: https://www.canceraustralia.gov.au/cancer-types/breast-cancer/breast-cancer-australia-statistics
[44] Cancer Australia, “Leukaemia in Australia statistics.” Accessed: Sept. 26, 2025. [Online]. Available: https://www.canceraustralia.gov.au/cancer-types/leukaemia/leukaemia-australia-statistics
[45] Cancer Australia, “Bowel cancer (Colorectal cancer) in Australia statistics.” Accessed: Sept. 26, 2025. [Online]. Available: https://www.canceraustralia.gov.au/cancer-types/bowel-cancer/bowel-cancer-colorectal-cancer-australia-statistics
[46] K. M. D. Merollini, L. G. Gordon, Y. M. Ho, J. F. Aitken, and M. G. Kimlin, “Cancer Survivors’ Long-Term Health Service Costs in Queensland, Australia: Results of a Population-Level Data Linkage Study (Cos-Q),” *Int. J. Environ. Res. Public. Health*, vol. 19, no. 15, p. 9473, Jan. 2022, doi: 10.3390/ijerph19159473.
[47] Australian Health Policy Collaboration, Victoria University, “Australian Health Services: too complex to navigate. A review of the national reviews of Australia’s health service arrangements,” Feb. 2019. [Online]. Available: https://www.vu.edu.au/sites/default/files/australian-health-services-too-complex-to-navigate.pdf
[48] “Database provided by the National Brain Cancer Advocacy Service (NAS).”
[49] “Home Care Packages.” Accessed: Sept. 26, 2025. [Online]. Available: https://www.myagedcare.gov.au/help-at-home/home-care-packages
[50] D. and A. Australian Government Department of Health, “Subsidy increase in the Home Care Packages Program.” Accessed: Oct. 08, 2025. [Online]. Available: https://www.health.gov.au/our-work/hcp/funding/subsidy-increase
[51] Australian Institute of Health and Welfare, “Cancer data in Australia, Cancer incidence and survival by histology (selected cancers).” Accessed: Oct. 08, 2025. [Online]. Available: https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/incidence-and-survival-histology-selected-cancers
[52] Cancer Australia, “Cancer Research in Australia: An overview of funding for cancer research projects and programs in Australia 2012 to 2020,” Jan. 2023. [Online]. Available: https://www.canceraustralia.gov.au/sites/default/files/migrated-files/publications/cancer-research-australia-overview-funding-cancer-research-projects-and-programs-australia-2012-

2020/pdf/cancer_of_funding_for_cancer_research_projects_and_programs_in_australia_2012_to_2020_final.pdf#page=32.07

[53] K. Aldape *et al.*, “Challenges to curing primary brain tumours,” *Nat. Rev. Clin. Oncol.*, vol. 16, no. 8, pp. 509–520, Aug. 2019, doi: 10.1038/s41571-019-0177-5.

[54] B. Y. Kong *et al.*, “Barriers and potential solutions to international collaboration in neuro-oncology clinical trials: Challenges from the Australian perspective,” *Asia Pac. J. Clin. Oncol.*, vol. 18, no. 3, pp. 259–266, 2022, doi: 10.1111/ajco.13606.

[55] “Dimensions AI | The most advanced scientific research database,” Dimensions. Accessed: Sept. 26, 2025. [Online]. Available: https://www.dimensions.ai/

[56] “World Population Prospects.” Accessed: Sept. 26, 2025. [Online]. Available: https://population.un.org/wpp/

[57] “Cancer Moonshot^{SM} - NCI.” Accessed: Sept. 26, 2025. [Online]. Available: https://www.cancer.gov/research/progress/moonshot-cancer-initiative

[58] “Cancer Research in the US Is World Class Because of Its Broad Base of Funding.” Accessed: Sept. 26, 2025. [Online]. Available: https://www.healthsciences.msu.edu/news/cancer-research-in-the-us-is-world-class-because-of-its-broad-base-of-funding

[59] “Cancer Treatment Research - NCI.” Accessed: Sept. 26, 2025. [Online]. Available: https://www.cancer.gov/about-cancer/treatment/research

[60] Johns Hopkins Medicine, “Accelerating Innovation in Cancer Care.” Accessed: Sept. 26, 2025. [Online]. Available: https://www.hopkinsmedicine.org/news/articles/2025/02/accelerating-innovation-in-cancer-care

[61] “Brain Tumor Trials Collaborative | Center for Cancer Research.” Accessed: Sept. 26, 2025. [Online]. Available: https://ccr.cancer.gov/neuro-oncology-branch/brain-tumor-trials-collaborative

[62] “Nine NHS Hospital Brain Tumour Centres Awarded Centre OF Excellence Status | Tessa Jowell Brain Cancer Mission (TJBCM).” Accessed: Sept. 26, 2025. [Online]. Available: https://www.tessajowellbraincancermission.org/news/nine-nhs-hospital-brain-tumour-centres-awarded-centre-of-excellence-status/

[63] B. Brockley, “World first trial to revolutionise treatment of brain cancer,” Cancer Research UK Cambridge Institute. Accessed: Sept. 26, 2025. [Online]. Available: https://www.cruk.cam.ac.uk/news/world-first-trial-to-revolutionise-treatment-of-brain-cancer/

[64] “We’re accelerating brain tumour research with £8m more for our Brain Tumour Centres of Excellence - Cancer Research UK - Cancer News.” Accessed: Sept. 26, 2025. [Online]. Available: https://news.cancerresearchuk.org/2024/09/24/8m-more-for-our-brain-tumour-centres-of-excellence/

[65] “Homepage,” Brain Tumour Foundation of Canada. Accessed: Sept. 26, 2025. [Online]. Available: https://www.braintumour.ca/

[66] H. Canada, “Details on transfer payment programs.” Accessed: Sept. 26, 2025. [Online]. Available: https://www.canada.ca/en/health-canada/corporate/transparency/corporate-management-reporting/departmental-performance-reports/2023-24-supplementary-information-tables/details-transfer-payment-programs.html

[67] “2023–24 Departmental Plan: Health Canada.” Accessed: Sept. 26, 2025. [Online]. Available: https://www.canada.ca/en/health-canada/corporate/transparency/corporate-management-reporting/report-plans-priorities/2023-2024-departmental-plan.html

[68] C. C. S. / S. canadienne du cancer, “Groundbreaking Canadian Cancer Society-funded research aims to reshape the future of advanced cancer,” Canadian Cancer Society. Accessed: Sept. 26, 2025. [Online]. Available: https://cancer.ca/en/about-us/media-releases/2025/breakthrough-team-grants

[69] J. Soares *et al.*, “DISP-12. BRAIN CANCER CANADA FUNDS CRITICALLY NEEDED RESEARCH AND ADVOCATES FOR PATIENTS, WITH THE AIM TO IMPROVE OUTCOMES FOR CANADIANS DIAGNOSED WITH PRIMARY MALIGNANT BRAIN

TUMOURS,” *Neuro-Oncol.*, vol. 25, no. Suppl 5, p. v139, Nov. 2023, doi: 10.1093/neuonc/noad179.0527.

[70] “Ontario Cancer Plan 2024 to 2028 – Cancer Care Ontario.” Accessed: Sept. 26, 2025. [Online]. Available: https://www.cancercareontario.ca/en/cancerplan

[71] “The Brain Cancer Group.” Accessed: Sept. 22, 2025. [Online]. Available: https://braincancergroup.com.au

[72] “Robert Connor Dawes Foundation.” Accessed: Sept. 22, 2025. [Online]. Available: https://rcdfoundation.org/

[73] The Centre for International Economics, “Review of the Australian Brain Cancer Mission.” The Centre for International Economics, Aug. 2023. Accessed: Sept. 25, 2025. [Online]. Available: https://www.health.gov.au/sites/default/files/2023-12/review-of-the-australian-brain-cancer-mission.pdf

[74] Australian Brain Cancer Research Alliance, “ABCARA.” Accessed: Sept. 25, 2025. [Online]. Available: https://www.abcara.com/

[75] “PoCoG Psycho-oncology Co-operative Research Group.” Accessed: Sept. 26, 2025. [Online]. Available: https://www.pocog.org.au/

[76] “The Brain Cancer Centre.” Accessed: Sept. 25, 2025. [Online]. Available: https://thebraincancercentre.org.au/

[77] M. Hong *et al.*, “The impact of brain cancer care coordinators on healthcare utilization and outcomes in patients with glioblastoma,” *Neuro-Oncol. Pract.*, vol. 11, no. 5, pp. 575–582, May 2024, doi: 10.1093/nop/npae030.

[78] “Matt ‘can’t imagine’ life without specialist brain cancer nurse support,” *ABC News*, Mar. 01, 2025. Accessed: Sept. 26, 2025. [Online]. Available: https://www.abc.net.au/news/2025-03-02/matt-stonham-brain-cancer-ordeal-nurse-elise-greedy/104946126

[79] S. S. Gorin, D. Haggstrom, P. K. J. Han, K. M. Fairfield, P. Krebs, and S. B. Clauser, “Cancer Care Coordination: a Systematic Review and Meta-Analysis of Over 30 Years of Empirical Studies,” *Ann. Behav. Med.*, vol. 51, no. 4, pp. 532–546, Aug. 2017, doi: 10.1007/s12160-017-9876-2.

[80] Brain Tumour Alliance Australia, “Brain Tumour Alliance Australia May 2025 Report,” May 2025. [Online]. Available: https://www.btaa.org.au/sites/default/files/BTAA-MAY-2025_FA_Digi.pdf

Australian brain cancer organisational profiles

Brain Tumour Alliance Australia

BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.
1800 857 221

Before 2000, Australians diagnosed with brain tumours had almost no dedicated support. While small informal groups existed, even the largest cities lacked consistent patient services, reliable information, or advocacy. In 2003, Canberra-based carer Denis Strangman, following the loss of his wife to glioblastoma, led the establishment of Brain Tumour Australia, the first national support group. Despite strong passion, this organisation closed in 2008 due to administrative difficulties. That same period saw the founding of the International Brain Tumour Alliance (IBTA) in 2005, with Denis Strangman as its inaugural Chair. IBTA is now a respected global voice, connecting people in more than 100 countries and advocating internationally for rights, equity, and improved care.

Mission, Objectives, & Focus

BTAA's mission is simple but profound: to Support, Inform, Represent and Connect people affected by brain tumours. Since inception, BTAA has grown into the peak national consumer and advocacy body for brain tumours in Australia — the trusted, independent voice that governments, researchers, clinicians and service providers engage with when seeking to understand the lived experience and priorities of the community.

Organisation Structure

In 2008, the BTAA was re-established by volunteers including Matt Pitt (Founding Chair), Denis Strangman, and Susan Pitt. Formally incorporated in 2009 as a not-for-profit organisation, BTAA was created to unite patients, carers, families and support groups across the country.

Key Successes & Commitments

For over 15 years, BTAA has delivered trusted, volunteer-driven services:

- Telephone Support Line — Australia's only dedicated national brain tumour helpline.
- Information Packs — over 2,000 distributed, tailored for adults, parents, and cultural communities.
- Support Groups — active in Canberra and Sydney, with mentoring of independent groups.
- Patient Forums — biannual events bringing leading clinicians together with patients and carers.
- Multilingual Resources — resources available in 10 key languages.

Informing and Connecting

As the peak advocacy body, BTAA amplifies the consumer voice through:

- A comprehensive website linking global resources, support groups, and patient stories.
- Monthly e-news and biannual magazine that reach thousands of Australians
- Representation at national and international meetings such as COGNO, SNO, and IBTA.

Representation and Advocacy

BTAA's role as peak body has been central to major national advocacy wins:

- Securing PBS listing for key treatments such as Temozolomide, Avastin, and most recently Vorasidenib.

- Advocating for dedicated brain cancer nurse coordinators for over a decade.
- Leading the establishment of the ABTC in 2022, which unites nine national organisations under one voice.
- Initiating Head to the Hill, the first national annual advocacy event at Parliament House.

Today

BTAA stands as Australia's peak consumer and advocacy body for brain tumours, predominantly volunteer-run and sustained by community and partnerships rather than large-scale fundraising.

By supporting individuals, informing communities, representing needs, and connecting organisations, BTAA ensures that the brain tumour community is no longer invisible — but is recognised, heard, and included in shaping national research, clinical care, and support priorities.

Future

The Australian brain tumour Landscape has evolved since 2003. Today there are many national foundations attempting to improve the impact from to patients, families and society.

BTAA is currently undergoing evolution and reformation to optimise the impact to the brain tumour community in the complex Australian brain tumour landscape.

This requires us to consider how we posture our committee, resources and the critical advocacy services we provide.

Over the next 6-12months, BTAA will remodel its strategic roadmap and transition into a contemporary fit for purpose national brain tumour advocacy organisation.

The Australian Brain Tumour Collaborative (ABTC)

The Australian Brain Tumour Collaborative (ABTC) was born from a discussion in October 2021 between the Brain Tumour Alliance Australia (BTAA) Chair and committee and then Shadow Minister for Health, Mark Butler. BTAA sought advice on how to raise government awareness of the dire impacts of brain tumours and ensure an appropriate national response. Mr Butler highlighted a major challenge: governments struggle to act when multiple consumer stakeholders approach the same problem from different perspectives. He recommended that, wherever possible, the brain tumour community should collaborate to provide a single united voice to government, offering a clear and coordinated understanding of the issues and solutions. In response, BTAA initiated and funded the establishment of the Australian Brain Tumour Collaborative — formally launched in December 2022.

Mission, Objectives, & Focus

Its purpose is to:

- Unite Australia’s brain tumour sector under one collaborative framework
- Align and integrate fragmented efforts across research, clinical care, and consumer support
- Amplify the lived experience voice to inform research, care and policy
- Drive national-scale action to improve outcomes and equity

The Collaborative’s objectives are as follows:

1. Identify and promote understanding of key gaps in services and support for people impacted by brain tumours.
2. Promote integration, partnerships and information sharing within the national brain tumour sector that better supports people impacted by brain tumours.
3. Promote patient-centred solutions to challenges associated with the survivorship journey for people living with brain tumours, drawing on evidence-based research and lived experience.
4. Individually and collectively advocate for better access to service coordination and ongoing supports for people with brain tumours, their families, and carers.
5. Continue funding for research and clinical trials to enable and accelerate better prevention, treatments, and care.

These objectives underpin all three pillars of the Australian Brain Cancer Landscape: Research & Trials (Objective 5), Clinical Care (Objectives 1, 3, 4), and Supports (Objectives 1, 2, 3, 4).

Organisation Structure

ABTC’s steering committee includes nine major national brain cancer foundations and organisations representing the full spectrum of the brain tumour journey — from laboratory research to end-of-life care, from clinical trials to psychosocial support:

- Brain Tumour Alliance Australia (BTAA)
- Mark Hughes Foundation
- Robert Connor Dawes Foundation

	• Peace of Mind Foundation • The Brain Cancer Group • Cure Brain Cancer Foundation • The Brain Cancer Centre • Cooperative Trials Group for Neuro-Oncology (COGNO) • Psycho-Oncology Co-operative Research Group (PoCoG) ABTC operates through a formal Steering Committee with Terms of Reference and a clear governance structure. A core theme is that while ABTC presents a united national voice, each member organisation retains its independence and vital connections to its community. The sheer number of national foundations involved — despite brain cancer being classified as a low-incidence cancer — reflects the complexity, diversity, and severity of brain cancer and its impacts.
Key Successes & Commitments	**Since its establishment, ABTC has:** • Advocated for a national brain cancer research and trials roadmap • Led national advocacy to secure government support for: a dedicated BCCC workforce, and the NAS • Consolidated data from programs such as BRAINS to inform clinical care and survivorship models • Brought unprecedented collaboration between formerly siloed research, support and clinical organisations • Presented a unified consumer voice to federal government **NDIS Priority Pathway** In late 2023, the NDIS implemented an undeclared policy that restricted brain tumour patients' access on the basis that they were generally palliative (and thus a State responsibility). ABTC led a nine-month national engagement effort with the Australian Government, partnering with NAS to present evidence and lived experience data on survivorship needs. This resulted in the reversal of the policy and the creation of a government-initiated priority pathway for brain cancer patients meeting access criteria — which remains in place, with NAS actively engaged and supporting departmental teams. **Advocacy for Dedicated Brain Cancer Care Coordinators** In 2023, the government announced the ACNNP to improve navigation support for all cancer patients. Despite 14+ years of lobbying, brain cancer was not allocated dedicated funding or nurses within the ACNNP model. **ABTC has since:** Led engagement with government and Department of Health to address this oversight Initiated and funded the landmark report 'Navigating the Unknown – A Call for Nationwide Brain Cancer Coordination' Submitted a 2025 pre-budget proposal calling for a National Brain Cancer Care Coordinator Framework

	This advocacy continues, with ABTC providing a unified national platform for ongoing government engagement on this critical gap.
What We Want to See for Brain Cancer in Australia	To realise its full potential, ABTC seeks: • Formal government recognition and support as a national voice for the brain tumour sector • Sustained funding for collaborative infrastructure, consumer engagement, and data-sharing systems • Inclusion in the governance of ABCM 2.0, the National Brain Cancer Research & Trials Roadmap, and reforms in Clinical Care and Supports The Australian Brain Tumour Collaborative embodies the principle that collective action achieves what no single organisation can. By uniting Australia’s leading brain tumour organisations, ABTC is building the environment needed to transform outcomes — delivering better research, more equitable care, stronger supports, and a more powerful voice for Australians living with brain tumours.

Robert Connor Dawes Foundation

The Robert Connor Dawes Foundation (RCDF) is a not-for-profit organisation headquartered in Australia with an office in the United States. The foundation was created in June 2013 by Liz Dawes and Scott Dawes in memory of their son Robert Connor Dawes who died from a brain tumour in April 2013 at 18 years of age.

We are battling paediatric brain tumours and supporting brain matters in the areas of research, care and development – to fund the science to end brain cancer and support patients in the meantime.

Mission, Objectives, & Focus

Our mission is to drive global paediatric brain cancer research advancements and support young patients while they are on their brain cancer journey. We achieve this through investing in Research, Care and Development.

Organisation Structure

The RCDF is led by Founder and CEO Liz Dawes. The governance team includes Scott Dawes, Director, and Michele Williams, Director and General Counsel, with Ellen Webb as Company Secretary. Dr Kim Wark serves as Head of Research, managing the research programs and partnerships. RCDF is supported by ambassadors and volunteers who help drive fundraising and advocacy.

Key Successes & Commitments

RCDF focuses on funding research, care, and development to improve outcomes for those affected. RCDF's impact includes funding an Australian-first mRNA vaccine for paediatric brain cancer in partnership with The University of Queensland, contributing $1.2 million towards a $2.4 million project. It also supports research through initiatives such as the Gideon Gratzer PhD Scholarship, which investigates new druggable molecules in high-grade gliomas, and the Grace Money Molecular Oncology Grant at the Royal Children's Hospital to advance precision medicine. International collaborations include the Alfie Chivers Fellowship at Hudson Institute, which focuses on identifying therapeutic targets for childhood brain tumours. These projects reflect RCDF's commitment to accelerating research and improving survival rates for young patients.

Research

We have raised over AU$17.3 M to support paediatric brain cancer research, funding basic science, translational projects, clinical trials, fellowships, scholarships and travel grants. We partner with like-minded, passionate organisations to achieve greater impact and have leveraged another AU$11.4 M through collaborative research initiatives.

We are active members of the

- DIPG collaborate
- Child's Brain Tumour Network (CBTN)
- Paediatric Neuro-Oncology Consortium (PNOC)
- Collaborative Ependymoma Research Network (CERN)

Care

We support infants, children, adolescent and young adults with brain cancer and their families or carers with in-home music therapy across Australia. Our qualified therapists have helped over 150 patients at different stages of their journey. We are about to begin a pilot program in the US with Wisconsin being the first area.

	Development Workforce capacity in this field is a challenge, and we want to be part of the solution. Building and inspiring the next generation of paediatric brain cancer researchers and clinicians, we have funded 5 PhD students and 9 postdoctoral scientists to date.
The Need — Why This Matters Now	Brain cancer is the most fatal of all childhood cancers. In the last twenty years, few new effective treatments have been discovered. 80% of children diagnosed with high grade tumours still lose their battle within 5 years. Current clinical treatments only help 50% of children, but leave 90% with lifelong physical and mental impairments.

Peace of Mind Foundation

Peace of Mind Foundation (POMF) is Australia's largest nationwide brain cancer support charity.

POMF was born out of love and loss. Caroline Matthews, who passed away on her 32nd birthday in 2011, inspired her husband Clint and his sister Bec to create POMF in 2013, recognising the critical need for compassionate support for families like theirs. POMF believes no family should face the journey of brain cancer alone. Every year, POMF supports over 1000 families across Australia, offering personalised, one on one supportive care programs and services from diagnosis through to bereavement. Introduced in 2021 as a program of POMF, the National Advocacy Service (NAS) delivers a vital service to brain cancer patients and their loved ones through a specialist team of advocates Australia wide. The program was developed in collaboration with Cure Brain Cancer and has exceeded expectations in growth and demand.

Mission, Objectives, & Focus	To give support, courage and a voice to the brain cancer community. POMF is Australia's leading brain cancer support charity with a sole focus on supportive care – the NAS delivers a distinct and unique support model to patients, families and by extension, to healthcare providers, through nation-wide telehealth supportive care via expert advocates. Supportive care programs and services to brain cancer patients and their families from diagnosis to bereavement. Key focus areas: • National Advocacy Service • Community Brain Cancer Navigator program • Counselling and financial aid • Retreat and community events
Organisation Structure	POMF was established in December 2013. It is made up of a board of directors (currently 8 non-operational directors), an executive team (CEO, COO, Program Managers) and other employees and volunteers, including 15 + staff (full-time and part-time) and 40+ volunteers. POMF is highly engaged in the health system, with over 650 health professionals now referring patients to their services, representing more than 180 hospitals and allied health providers across Australia. POMF is funded entirely by donations and partnerships. Key partnerships across POMF programs include Cure Brain Cancer Foundation, Geelong Hospice Foundation, Zoe's Fight, APCO, All About Art, Australian Brain Cancer Foundation, and Superheroes Foundation (Funding of POMF's financial grants program - small grants provided to brain cancer patients to support financial needs).
Key Successes & Commitments	• Since its inception in 2021, the NAS has supported ~3,000 families, walking alongside them through some of the most challenging moments of their lives. Each family's situation is unique, and POMF's commitment to providing compassionate, tailored support remains at the heart of everything they do. The reach of the NAS continues to expand, with more than 1000 families now receiving support annually. This growth has been made possible through the trust and collaboration of over 650 health professionals who refer families to the service, and through partnerships with nearly 180 hospital and allied health services across the

country. These relationships are vital, ensuring that families are connected to the right support at the right time.

- A significant milestone has been the development of a prioritised pathway with the NDIS for patients with high-grade tumours. Our advocacy team now works closely with the NDIS, resulting in faster access times and a more case-managed approach for families navigating this complex system. This collaboration is already making a tangible difference in the lives of those we support.
- We are also committed to education and awareness, delivering presentations to hospitals and clinical teams across the country. These sessions ensure that our work is not only understood but also integrated into clinical practice, helping more families benefit from the support we offer. Our Foundation also informs many academic research studies and programs, supports advisory bodies, advocacy bodies and research organisations. Members of the POMF team sit on the advisory boards of more than 15 research projects nationally and internationally, from survivorship and quality of life studies to clinical trials. We continue to ensure that the voice of the patient and their family is not just heard but actively shapes the future of brain cancer care.
- POMF’s brain cancer retreats are unique worldwide – no other organisation globally running retreats specifically for men and women diagnosed with brain cancer.

The Need — Why This Matters Now

The demand for support services from the brain cancer community has rapidly grown and now exceeds the resources of POMF with the volume of referrals flowing from the medical community and by private referral – with demand far outpacing the capacity of the NAS. Dedicated brain cancer support sits outside of the health framework. Over 74% of referrals we receive annually come from healthcare professionals, including BCCCs, social workers and clinical nurse consultants – highlighting that we are providing services and supports that the health system is not currently providing or funding. We also know that there is an overwhelm of unmet needs for this patient cohort that the current health system is not keeping up with, reinforced by the number of referrals received.

What We Want to See for Brain Cancer in Australia

From our work supporting more than 1000 families every year, we see several systemic gaps and inequities that urgently need addressing:

- **Fragmented Care and Navigation:** Patients and families often describe feeling “lost” after diagnosis. Unlike other cancers, there are very few specialist BCCCs or navigators to help families understand treatment options, connect to services, or access financial and psychosocial support. We regularly hear from families who spend weeks searching for the right information – utilising precious time they cannot afford to lose.
- **Limited Access to Specialist Support Services:** There is a shortage of neuro-oncologists, neuropsychologists, and rehabilitation services, particularly outside metropolitan centres, creating inequities for people living in regional and rural areas. Many families we support in regional areas must travel hours for every major appointment, placing enormous financial and emotional strain.
- **Psychosocial Support Gaps:** Brain cancer is unique in that it often affects cognition, personality, and behaviour, creating immense pressures on carers and families. Yet, there are very few dedicated psychosocial or counselling services tailored to brain cancer. Many families tell us they feel invisible in the system, whilst carrying a heavy emotional and financial load.

- **Research Inequities:** Brain cancer receives a disproportionately small share of cancer research funding relative to its mortality rate. This under-investment contributes to poor survival rates, limited clinical trial options, and few new treatment pathways. Families are often forced to look overseas for experimental treatments, which are financially inaccessible for most.
- **Financial Strain:** Because of the cognitive and physical impacts of the disease, patients often lose their ability to work very early in their diagnosis, while carers may also leave employment to provide full-time care. With little structured financial support available, many families face significant hardship on top of the emotional toll.

The systemic gaps in care, research, and support for brain cancer patients in Australia - fragmented care, under-resourced services, inequitable access, underfunding of research, and inadequate psychosocial and financial support creates a situation where families not only battle a devastating disease, but also the system itself.

There is an opportunity to create a more unified national approach to brain cancer care, bringing together hospitals, researchers, support organisations, and government. Coordinated care pathways and standardised guidelines would help ensure patients, no matter where they live, have access to timely and consistent treatment and support. There is value in expanding patient advocacy (through the NAS) and patient navigation services through the expansion of dedicated BCCCs to improve patient and family experiences. POMF has seen firsthand how even modest increases in navigation and psychosocial support can reduce stress, improve quality of life, and keep families connected to services. Scaling these supports nationwide could make an immediate impact.

The Brain Cancer Centre

In May 2015, Carrie Bickmore OAM won the prestigious Gold Logie at the TV Week Logie awards, which she dedicated to her late husband Greg who passed away five years earlier following a 10-year battle with brain cancer. Carrie went on to form the CB4BC Foundation which has raised over $27m and aims to fund medical research into the horrible disease that is brain cancer. CB4BC is a passionate, community-driven organisation dedicated to raising awareness and funds for brain cancer research. Our aim is always to ensure that as much money as possible gets into the hands of researchers who are working to find a cure.

In 2021, CB4BC founded The Brain Cancer Centre (BCC), established in partnership with the Walter and Eliza Hall Institute and other partners to bring together the best and brightest medical research minds with a focus on brain cancer. Working together to bring us towards our vision: that one day no lives will be lost to brain cancer.

Mission, Objectives, & Focus

The BCC is a world class research ecosystem where we bring together the best and brightest minds driven by a single Vision: That one day, no lives will be lost to brain cancer. Our strategy is simple, we have to fund collaborative research programs and clinical trials while bringing together incredible people as often as possible to make progress into this disease. We bring together phenomenal talent, infrastructure and experience from leading hospitals, medical research institutes and universities from across Australia and the world.

Our world-class research teams work collaboratively to develop new treatments and trials so that patients diagnosed with brain cancer are given real hope.

Key Successes & Commitments

Since launching the BCC we have:

- 112 local, national and international collaborations
- 13 formal research and clinical trial partnerships are in place with institutions and hospitals around the country
- There are no less than 6 clinical trials based on BCC research
- There are over 50 papers published in internationally respected scientific journals since launch which credit the BCC with supportive funding, the same number as in 2023
- 90 researchers are now part of the BCC, including 24 early career post-doctoral researchers and 19 students
- 32 consumers have contributed to programs across the BCC,

Since the initial contribution of $10M donation from Carrie's Beanies 4 Brain Cancer to establish the Brain Cancer Centre in Oct 2021, $47,766,197 has been leveraged in other philanthropic, state and federal government grants.

Despite our knowledge of marked variations in the response of different brain cancers to treatment, there is little understanding about the drivers of the differences, and a lack of identifiable biological characteristics – biomarkers – that can predict recurrence or determine the best treatment for individual patients.

	No new, effective treatments have been found, despite more than 1000 clinical trials conducted in brain cancer in the past 2 decades. Neuro oncology clinicians and researchers acknowledge a new approach is required to improve treatment and outcomes for brain cancer patients. **The Brain Cancer Centre's radical approach** • The Brain Cancer Centre's Brain Perioperative Clinical Trial Program (Brain POP) is the world's first perioperative (or 'Window of Opportunity') clinical trial program for brain cancer. • It was initially supported by an investment of $16M from the Victorian State Government. • Tumour biopsies are taken before and after treatment to provide critical information to guide further drug development. • For the first time, researchers are being able to directly observe the effect treatment has on a patient's brain cancer by comparing tumour samples from before and after treatment. • Our neuro oncology clinical trial teams are some of Australia's most experienced • Brain POP is active now with trials completed and open to brain cancer patients. A clinical trial in low grade glioma has recently completed recruitment (*A perioperative study of safusidenib in patients with IDH1 mutated glioma)* ***with results published in the internationally renowned***
The Need — Why This Matters Now	We have the ability to lead the world efforts to make progress into this disease if we fund it properly. We have the community momentum, the institutional engagement and the environment for a national effort that will provide significant gains in survival. This can be the cancer that we solve. But we won't do that if we rely on philanthropy and sub-optimal amounts of funding with complex and competitive systems. We need to fund the ideas that are already working – put the resources around the established collaborative centers that are showing that this new system of team science can work. This disease kills kids and people in the prime of their lives under 40. By the Australian Governments own calculations via the Office of Impact Analysis, the value of a statistical life is $5.4M. Each year, brain cancer takes the lives of 1,500 of those young people and other adults. That's $8.1B of lost value in society – each year – based on the idea that these people who fight and die from this disease should live to be incredible contributors to our society. The investment in helping drive up survival and quality of life will repay multiple times over.
What We Want to See for Brain Cancer in Australia	A new model for investment into dedicated Brain Cancer Centers of Research Excellence that allows the strengthening of the current skills and technologies and creates the vehicle for accountability and real progress. Given access to funding that is built around the strategic objectives of each of the centres will allow for a paradigm shifting leap in our progress and current ways of working. Allocation of that funding on a multi-year cycle and via strict and transparent reporting and progress monitoring will provide confidence to the Government, the public and most importantly, provide real hope for patients.

The Mark Hughes Foundation (MHF) & MHF Centre for Brain Cancer Research

The Mark Hughes Foundation (MHF) is an Australian charity dedicated to raising awareness and funds for brain cancer research. Founded by former rugby league star Mark Hughes and his wife Kirralee, the organisation works tirelessly to improve outcomes for individuals diagnosed with brain cancer, as well as to support their families and carers. The MHF was established in 2014 after Mark Hughes was diagnosed with brain cancer and is based in Newcastle, New South Wales, but serves communities across Australia. The foundation is driven by a personal mission to improve survival rates and treatment options for brain cancer patients.

The Mark Hughes Foundation Centre for Brain Cancer Research (MHF Centre) was formed in 2022 as a partnership between the Mark Hughes Foundation and the University of Newcastle. It began with a chair, Professor Mike Fay, and now has more than 40 employees, including more than 20 post-docs and PhD students all working on the challenge of brain cancer.

Mission, Objectives, & Focus	The objectives of the MHF are: • To raise vital funds for brain cancer research, aiming to increase survival rates and discover better treatments. • To increase public awareness of brain cancer and its impact in Australia. • To provide support and information to patients, families, and carers affected by brain cancer. The MHF Centre shares the community vision of three critical pillars; Patient Support, Clinical Care and Targeted Research. We aim to drive a Team Australia approach to these pillars to ensure that no patient is left behind. A brain cancer patient in rural Australia deserves the same standard of care as on in the big city.
Organisation Structure	The MHF Centre has over 120 members nationwide and has six dedicated research streams. These scientific stream leaders and their deputies are driving change through research and practice in brain cancer. With a focus on research and patient-outcomes, we are collaborating with research teams nationwide to develop better treatments and patient care. 1. Patient Experience led by MHF Chair and Director Prof Mike Fay with Deputy Cath Adams 2. Brain Cancer Imaging led by A/Prof Saadalah Ramadan and Deputy Dr Bryan Paton 3. Experimental Therapeutics led by A/Prof Paul Tooney with Deputy Dr Lucy Corke 4. Blood Based Biomarkers led by Dr Richard Lobb and Deputy Dr Zhen Zhang 5. Translational Neuroscience led by Prof Hubert Hondermark and Deputy Dr Chen Chen Jiang 6. Paediatric Brain Cancer led by Prof Matt Dun and Deputy Dr Catherine Johnson. Our research leaders are supported by professional staff including: • Centre Manager: Kylie Hugo • Patient Experience and Clinical Trials: Trudi Wynne • Communications and Engagement: Linda Drummond • Centre Coordinator: Emily Callaghan and Sally Wivell

	• Translational Research Coordinator: Sandy Nixon
Key Successes & Commitments	**Key success of the MHF include:** • Millions of dollars raised for brain cancer research and support since its inception. • Significant contribution to the establishment of a brain cancer research centre in collaboration with the University of Newcastle; as well as supporting extensive brain cancer research in Australia. • Developed and implemented a model of brain cancer care co-ordination to help patients and their families through this journey • Improved national awareness of brain cancer, resulting in increased advocacy and support. **Key success of the MHF Centre include:** • **The MHF Brain Cancer Biobank:** established in 2014 and now holds samples from over 400 patients. These include bloods, tumour samples as well as novel whole brain donations. The team collaborates globally, with researchers across the nation and the world now accessing our samples to support and drive their research. • **The MHF Brain Cancer Care Coordinators:** an integral part of patient support and advocacy. Funded by the MHF and now through the MHF Centre, our Brain Cancer Care Coordinators are embedded in our health districts and communities offer unique support, advocacy and care during this most difficult and challenging time. The MHF Centre now has six BCCCs in the Hunter New England footprint, servicing over 1000km in NSW - down to the Central Coast and up to the Queensland border. Based in the John Hunter Hospital, Tamworth Hospital, Coffs Harbour and Port Macquarie Hospitals, our BCCCs are always on the phone, in the car, or in clinic for our patients. We are currently in the process of employing our sixth BCCC, a specialist paediatric nurse to care for our youngest patients. The impact of our BCCCs in providing optimal patient care for brain cancer patients is outlined in an article titled *Care Coordination: The experience of a Brain Cancer Care Coordinator in Australia*, published in the journal *Neuro-Oncology*. We need to take a Team Australia approach to fighting brain cancer, as we're decades behind research of other cancers. We've teamed up with the Brain Cancer Centre Team at WEHI to do a horizon scan to see who's out there and what they're doing so we can take a tactical approach.
The Need — Why This Matters Now	Philanthropic Brain Cancer organisations have been leading the way in the brain cancer space. Australia has the opportunity to lead the world in this field, but we need Government help. The ABCM was a good starting point, but we need to go further for 2.0. Brain cancer researchers, patients and philanthropy are a strong team, who can be stronger with government support. With a truly collaborative model, a platform of targeted research funding and governance we can make a real difference. The ABCM demonstrated our ability for us to work together, and showed how much philanthropic funding was being put to brain cancer. Next step, make funding more equitable and Australia-wide.

What We Want to See for Brain Cancer in Australia

Recommendations:

1. Work collaboratively with philanthropic funders to co-fund research
2. Dedicated BCCCs rolled out nationwide – Federal oversight and commitment, with state/territory support.
3. Federal governance for better treatments and equity for brain cancer patients – e.g.: PBS listing for drugs for all cancer patients including brain cancer. Faster rollouts of clinical trials.

What we can do:

- Advise on key research needs, pull together the teams, and co-fund research with government.
- Form centres of research excellence.

What the Government can do:

- Medications listed on PBS – all cancer treatments for all cancer patients
- Streamlining clinical trials
- Work with states and territories on meaningful care for patients (BCCCs as a model)

The Brain Cancer Group

The Brain Cancer Group

The Brain Cancer Group (TBCG, formerly the Sydney Neuro-Oncology Group Ltd) was established in 2000 by dedicated neurosurgeons Dr Raymond Cook and Dr Michael Biggs. Based on the Royal North Shore Hospital campus in Sydney, Australia they recognised the need to improve care and treatment for brain cancer patients; a cohort with life changing diagnoses, yet who stood largely alone in the community with little support.

Today, TBCG Board of Directors comprises a multidisciplinary team, all bringing their expertise as well as their time to improve the lives of brain cancer patients: we have Clinical Board Directors representing all the disciplines required in the treatment of brain cancer, providing invaluable expertise and insight for effective collaboration and support. Complimenting the clinical specialists are experienced non-clinical Board Directors with commercial and organisational skills. A key feature is the operational focus on directing clinical expertise to shape our programs.

Mission, Objectives, & Focus	TBCG is committed to improving the care and outcomes for patients with brain cancer. With the motto *care2cure*, TBCG dedicates their time and expertise voluntarily, to drive brain tumour research, education, and patient and carer support.
Organisation Structure	TBCG is focused on improving patient outcomes across the spectrum – from patient care to working towards finding a cure for this devastating disease. With the synergy arising from our medical oncologists, radiation oncologists, surgeons, researchers, nurses, patients and carers all working together, we can deliver meaningful programs across our 3 pillars: Research, Education and Support.
Key Successes & Commitments	TBCG's Research pillar is dedicated to furthering our understanding of brain cancers, and importantly, using this knowledge to develop and improve treatment for patients. Our research spans from pre-clinical translation research to clinical research and trials. To understand the interplay between molecular findings in the laboratory, treatment and patient outcomes, TBCG funded the development of the TBCG Databank in 2021. The TBCG Databank comprises three components: Tissue Biobank, Clinical Outcomes Database, and the Brain Imaging Laboratory. The linkage of all 3 components becomes a powerful tool for clinical decision-making and is ideal for bench-to-bedside research. In collaboration with the Bill Walsh Translational Cancer Research Lab, Kolling Institute, our pre-clinical research team leverages TBCG's Databank to identify better treatment regimens and to discover novel treatment approaches in brain tumour patients. The established pathways for the routine collection and analysis of brain tumour samples paired with patient treatment outcomes enables them to gain better insight into how brain tumours work. Projects like these help us understand why patients with seemingly similar brain tumours, and who are therefore receiving similar treatment, may be responding differently to treatment. In recent years, the team has established numerous research models in the lab that form the essential building blocks from which we can strive to develop new treatment options for brain cancer patients. TBCG is invested in the training of early-career researchers and this year supported PhD students, a medical student and Honours student in their research projects. We are in the process of establishing a full-time PhD Scholarship with The University of Sydney, with the first recipient anticipated in 2026. TBCG also supports a number of clinical trials including the MANGO trial conducted by the Brain Imaging Laboratory. Brain cancer research is desperately needed to discover new treatments and improve patient outcomes.

The Need — Why This Matters Now	At TBCG, we believe that access to accurate, high-quality information is essential to empowering patients and their families throughout their brain cancer journey. We host an Annual Brain Cancer Awareness Raising event at NSW Parliament House during Brain Cancer Action week in May. This year, we shone a spotlight on the disparities in brain cancer care across regional New South Wales with data revealing significant gaps in access and outcomes. The evening brought together medical professionals, patients, carers, policymakers, and advocates committed to improving outcomes for those affected by this devastating disease. An integral part of our Education Pillar is our collaboration with national organisations such as the Cooperative Trials Group for Neuro-Oncology (COGNO) and the Brain Tumour Alliance Australia (BTAA). By partnering with organisations that share our vision and values to raise awareness and to fund our programs, results can be achieved in an efficient manner. Throughout the year, TBCG and BTAA co-host up to 4 patient and carer education events held on the North Shore Medical Campus, Sydney, Australia or delivered virtually. We also partner with BTAA and COGNO to deliver a one-day national patient and carer education forum during COGNO's Annual Scientific Meeting — a flagship event that connects patients with the latest developments in neuro-oncology research and care. These forums are not only a source of reliable information — they are a vital space for connection, support, and shared understanding. Attendees consistently highlight the opportunity to meet and engage with others facing similar challenges, as well as to speak directly with healthcare professionals and researchers. Our collaboration with COGNO and BTAA allows us to deliver these events on a truly national scale — ensuring that no patient or carer, regardless of location, is left without access to relevant, timely, and high-quality information. To extend our reach, we record all educational events and make them freely available on our YouTube channel, offering ongoing access to trusted information for anyone unable to attend live. In addition to educating patients and carers, we also take part in educating other health professionals. Our neuro-oncology Nurse Practitioner, Marina Kastelan, is often invited to speak at various conferences and symposiums throughout the year. At the core of our Support Pillar is our Neuro-Oncology Nurse Coordination Programme. To address the immediate and ongoing needs of brain cancer patients, TBCG supports the salary of a dedicated Nurse Practitioner who coordinates the care of each patient and guides them through their brain cancer journey. They can provide advanced clinical assessment, prescribe medications, refer patients to Allied Health professionals; all in full collaboration with their multi-disciplinary team of specialists including Neurosurgeons, Medical Oncologists and Radiation Oncologists. They guide patients and families through their brain cancer journey by providing a single point of contact. Our Nurse Practitioner, Marina Kastelan is currently the only specialist in Neuro-Oncology in Australia. She sees 120 new patients a year, has provided her expert opinion to 5 Academic and Government Organisations, and has given 10 *invited* presentations to Academic, Patient & Government Forums. Just one phone call away, Marina's expertise and dedication is an invaluable source of support for countless patients and their families.

What We Want to See for Brain Cancer in Australia	One Australian is diagnosed with brain cancer every 5 hours. The most common malignant brain tumour, glioblastoma, has a poor prognosis with a median survival of 18 months. Compared to breast and prostate cancers which have a 5-year survival rate of 89.4% and 95.2% respectively, the brain cancer 5-year survival rates are at a mere 27.7%. As a registered charity, we rely on the generous support of our donors to continue our support, research and education programs for brain cancer patients. Despite the collaborative efforts of the brain cancer community so far, survival rates have only marginally improved in the last 20 years. A brain cancer diagnosis can impact a patient’s ability to drive, their cognition, ability to move, and family life. We ask the Government to expand support and education programs for Australians living with brain cancer, and work to alleviate the high disease burdens placed on brain cancer patients and their families while investing in research to improve treatment outcomes.

Cooperative Trials Group for Neuro-Oncology

COGNO	COGNO was established in 2007 to enable a coordinated approach to developing multi-centre neuro-oncology clinical trials for Australians affected by brain cancer.
Mission, Objectives, & Focus	COGNO's Mission is the achievement of better health outcomes for patients and those affected by brain tumours through clinical trials research. COGNO is a large (>1000 member) trials network of healthcare professionals, researchers and consumer representatives dedicated to improving survival and quality of life for people affected by brain and spinal tumours. COGNO is the leading trials group in Australia and New Zealand (ANZ), dedicated to improving outcomes in adults with this devastating disease. Clinical trials are pivotal to enable new treatments to be tested, proved and translated effectively into clinical practice to improve survival and quality of life for those impacted. COGNO leads as well as collaborates with national and international partners to design, develop and support the conduct of innovative, next-generation brain cancer clinical trials and research. COGNO trials are accessible via a network of sites with reach across Australia. To date, COGNO trials have been supported through competitive funding from the NHMRC, Cancer Australia, MRFF and the Australian Brain Cancer Mission. Visit COGNO's Clinical Trials page to learn more.
Organisation Structure	COGNO is one of 14 collaborative Cancer Clinical Trials Groups established by the Australian Government under the Cancer Australia Support for Cancer Clinical Trials Program, which provides core infrastructure support for trial design and development, but not trial execution. COGNO also provides educational updates about relevant practice-changing brain tumour trials and research. Over 1150 people have become COGNO members over the last 18 years. COGNO members come from a diverse range of backgrounds, with 17 disciplines represented including medical and allied health professionals, translational science / imaging researchers and those with clinical trial expertise. Associate membership is open to consumer advocates and to industry partners. COGNO has key leadership Committees including the Management Committee and Scientific Advisory Committee who appraise and vet new concepts and trials for development.
Key Successes & Commitments	The rarity of primary brain cancer and the geographic distribution of care across Australia, means there are still significant disparities and inequities faced by brain cancer patients in timely access to both high quality care as well as cutting-edge clinical trials, which occurs in predominantly metropolitan and large regional centres. Referral to trial sites could be further streamlined and better systematised. COGNO is deeply committed to ensuring that every person diagnosed with primary brain cancer is given the opportunity to access timely molecular profiling of their cancer, paired with access to a suite of clinical trials, tailored by precision medicine, of both novel treatments and supportive care interventions.
The Need — Why This Matters Now	To date, COGNO-led trials have been funded solely through competitive grant mechanisms and sources including the NHMRC, Cancer Australia, MRFF and the Australian Brain Cancer Mission. As such, very significant resources and time have been invested into these funding applications which are highly competitive, with no guarantee of success. This significantly slows the pace of trial delivery, innovation and impact for every patient affected.

	A key example on future opportunities includes the proposed COGNO-led CARAT adaptive platform trial in adult Glioblastoma. The platform trial design carries the potential to comprehensively profile tumours but also efficiently compare multiple interventions against a single control group. This proposal has been submitted to the MRFF for funding (currently under review). The CARAT platform has immense potential for future expansion and to leverage funding via strategic partnerships with both industry partners and philanthropic foundations.
What We Want to See for Brain Cancer in Australia	That a meaningful investment be made to core infrastructure funding for clinical trials in brain cancer that would uplift and enable access for every person diagnosed with primary brain cancer. That resources be committed to enable COGNO to deliver its ambitious vision for a comprehensive Australia-wide trials program across metropolitan and regional/rural/remote settings, with a focus on providing novel trial access to all, especially priority populations highlighted with the Australian Cancer Plan.

The Psycho-oncology Co-operative Research Group

PoCoG Psycho-oncology Co-operative Research Group	The Psycho-oncology Co-operative Research Group (PoCoG) is an organisation of more than 2000 health professionals and researchers working to improve the psychological care of people affected by cancer. Our work focuses on caring for the whole person from the time of diagnosis throughout the whole cancer journey. It is also about increasing people's ability to enjoy life and achieve psychological resilience in the face of a disease that can be both chronic and life-limiting.
Mission, Objectives, & Focus	PoCoG aims to improve outcomes for people affected by cancer by: • Developing and facilitating high quality interventions and services that optimise psychosocial and supportive care. • Supporting health professionals and researchers with advice and resources that increase collaboration and innovation in psycho-oncology. • Bringing together health professionals, researchers and consumers to share ideas and collaborate. • Building capacity and collaborations to conduct large, multi-centre research of clinical relevance that would be difficult for a single team to undertake. • Encouraging other trials groups to include psychosocial or quality of life sub-studies in existing and planned research.
Organisation Structure	The Psycho-oncology Co-operative Research Group (PoCoG) operates as a Cancer Australia-funded Cancer Cooperative Trials Group, bringing together a multidisciplinary network of healthcare professionals and researchers focused on improving psychological, emotional, and survivorship care for people affected by cancer. Its structure includes a Board of Directors providing governance, an Executive Team comprising a Chief Executive Officer, Chief Operating Officer, and Program Managers overseeing operations and research programs, supported by staff and volunteers. PoCoG also works closely with advisory committees and special interest groups to guide research priorities and ensure consumer engagement, enabling the organisation to lead national and international psycho-oncology trials and initiatives.
Key Successes & Commitments	PoCoG runs and supports innovative, high-quality, psycho-oncology research with the greatest potential to improve outcomes for people with cancer, their carers and families, healthcare professionals, and the health system. PoCoG also seeks to facilitate research that helps address the needs of priority groups including First Nations Australians, older people with cancer, people with an experience of a poor-prognosis cancer, people living in rural and regional areas, and people from culturally & linguistically diverse communities.

Cure Brain Cancer Foundation

Cure Brain Cancer Foundation	Founded in the early 2000s (originating as the Cure for Life Foundation) to accelerate research and improve outcomes for people with brain cancer in Australia. Evolved into Cure Brain Cancer Foundation (CBCF), the national charity focused on research, advocacy, patient support, and awareness.
Mission, Objectives, & Focus	**Mission:** Rapidly increase survival and improve quality of life for people impacted by brain cancer; ultimately find a cure. **Strategic pillars** • Research funding across the pipeline (discovery → translational → clinical), prioritising high-impact, collaborative science. • Advocacy & awareness to unlock policy change and investment; give patients and carers a strong national voice. • Patient support & navigation through partnerships (e.g., National Advocacy Service), improving access and outcomes.
Organisation Structure	• Board of Directors providing governance and strategic oversight. • Executive Team leading operations and delivery. • Scientific/Medical Advisory Committee guiding research priorities and peer review.
Key Successes & Commitments	**GBM AGILE (Adaptive Global Platform Trial) in Australia** • CBCF made a major funding commitment to enable GBM AGILE trial activity in Australia, supporting trial site start-up and patient access. • Catalysed multi-party co-funding and raised the profile of adaptive platform trials for glioblastoma. **Scholarships & Fellowships** • Multi-year Early-Career Fellowships and PhD scholarships to build the next generation of Australian brain cancer researchers. **Research Trials & Collaborative Grants** • Portfolio spanning priority-driven grants, proactive investments and co-funded initiatives with national and international partners.
The Need — Why This Matters Now	• Five-year survival for brain cancer in Australia remains stubbornly low, with only modest improvement over decades. • High burden and limited treatment options; access to innovative trials remains uneven and often delayed.

What We Want to See for Brain Cancer in Australia	• Sustained funding for the National Advocacy Service (NAS): Scale a national navigation and advocacy service that provides hands-on help with NDIS, Centrelink, My Aged Care and local supports; secure multi-year funding to meet rising demand. • Faster, broader access to novel clinical trials: Expand Australian participation in adaptive and platform trials (e.g., GBM AGILE) with streamlined start-up, harmonised ethics/governance, and patient travel/accommodation supports so geography doesn't determine access. • Talent pipeline & research continuity: Protect and grow fellowships and translational grants to keep top talent in Australia and accelerate first-in-human studies. • Long-term, coordinated investment: Lock in a national roadmap with government–philanthropy–industry codesign, tying funding to measurable survival and quality-of-life gains. **Outcome Targets** • Lift five-year survival significantly by: (a) increasing clinical-trial participation, (b) speeding trial set-up/start times, and (c) scaling navigation so more patients reach the right treatment at the right time.

Disclaimer

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ALLIANCE AUSTRALIA Inc.
1800 857 221

www.btaa.org.au

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