Brain Tumour Alliance Australia

HEAD TO THE HILL 2026

ADVOCATE KEY MESSAGES - OUR THREE CORE ASKS

One Voice. One Community. One National Call to Action.

You do not need to cover everything. Choose the message that best connects with your story and make one clear ask.

1. RESEARCH & CLINICAL TRIALS

KEY MESSAGE **Australia has a major opportunity to turn the $50 million Commonwealth Medical Research Future Fund (MRFF) investment into better outcomes through a co-designed national Brain Cancer Research and Trials Roadmap.** Future priorities should be shaped with patients, carers, clinicians, researchers and the brain tumour sector, with a focus on unmet need, clinical trials and translating research into better treatments and outcomes.

OUR ASK **We are asking the Australian Government to partner with BTAA and the Australian Brain Tumour Collaborative to co-design the next phase and implementation of the Brain Cancer Research and Trials Roadmap, including how the $50 million MRFF investment is prioritised.**

YOU COULD SAY *"We welcome the $50 million investment. Please make sure the brain tumour community has a genuine seat at the table in deciding where that funding goes and what research is prioritised."*

REMEMBER **Co-design. • Target unmet need. • Turn research funding into outcomes.**

2. CLINICAL CARE - NATIONAL BRAIN TUMOUR NAVIGATOR PROGRAM

KEY MESSAGE **Every Australian diagnosed with a brain tumour should have access to a specialist navigator, regardless of where they live.** There are only 29 Brain Cancer Care Coordinators nationally (20.6 FTE), with access heavily concentrated in major east-coast cities. Specialist navigators help coordinate complex care from diagnosis through treatment, survivorship, recurrence and end-of-life care.

OUR ASK **We are asking the Australian Government to fund and support a National Brain Tumour Navigator Program aligned with the Australian Cancer Nursing and Navigation Program. The proposed model is $8.75 million, including 23 specialist navigator positions.**

YOU COULD SAY *"Your postcode should not determine whether you have specialist brain tumour navigation. Please support a national program so every patient and family has someone helping them through the system."*

REMEMBER **Specialist navigation. • National access. • No postcode lottery.**

3. SUPPORT SERVICES - CO-FUND THE NAS

KEY MESSAGE **NAS is a proven, brain-cancer-specific service that helps patients and families navigate Commonwealth support systems.** Delivered by Peace of Mind Foundation, NAS helps with the NDIS, Centrelink, aged care and other essential supports. In 2025, 322 of 326 NAS-supported NDIS applications were approved.

OUR ASK **We are asking the Australian Government to co-fund the NAS at $725,000 per year for three years, alongside existing sector and partner investment. This is a co-funding request - not a request for Government to fund the entire service.**

YOU COULD SAY *"We're asking Government to partner with the sector and co-fund the NAS - $725,000 a year for three years, not the full cost of the service."*

REMEMBER **Co-funding. • Partnership. • Proven national service.**

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KEY BRAIN CANCER STATISTICS

Use one or two statistics that connect most naturally to your story.

Every day, 6 Australians are diagnosed with brain cancer. Around 2,098 Australians were estimated to be diagnosed in 2025.

Every day, 4–5 Australians die from brain cancer. An estimated 1,639 Australians died from brain cancer in 2025.

Brain cancer kills more Australians each year than our roads do. In 2025, there were an estimated 1,639 brain cancer deaths, compared with 1,309 road deaths across Australia.

Brain cancer kills more young Australians than any other cancer. The Australian Government has reported that brain cancer kills more Australians under 25 than any other cancer.

Brain cancer is the leading cause of cancer death in Australian children. In the latest published childhood cancer mortality data, brain cancer caused 33 deaths among children aged 0–14, more than twice the number caused by leukaemia.

For the most common aggressive brain cancer, only around 1 in 16 people survive five years. Glioblastoma, IDH-wildtype accounted for 64% of brain cancers diagnosed in 2021, with five-year survival of just 6.3%.

Brain cancer survival has barely moved in a generation. Overall five-year survival increased from just 21% to 24% over three decades.

Brain cancer causes a disproportionate number of cancer deaths. It represents only 1.2% of new cancer diagnoses, but 3.1% of all cancer deaths in Australia.

SURVIVAL IS ONLY PART OF THE STORY

For many people, surviving a brain tumour does not mean returning to the life they had before diagnosis.

Only around 1 in 4 people diagnosed with brain cancer survive five years. The current Australian five-year relative survival rate is 24%.

Brain cancer can leave people living with permanent neurological disability. Tumours and treatment can affect memory, concentration, speech, movement, behaviour, judgement and independence.

Cognitive problems appear particularly severe in people with brain and CNS cancers. In a large study comparing 12 cancer groups, 86.5% of people with brain/CNS cancer reported some cognitive difficulty and 51.3% reported moderate-to-severe difficulty — the highest proportion of moderate-to-severe cognitive problems of any cancer group studied.

The disability needs of people with brain tumours can be enormous. Australian sector research reports average NDIS plans for brain tumour patients of around $230,000–$300,000 — approximately four to five times the national NDIS plan average cited in the report.

The impact extends well beyond medical treatment. Survivors may need rehabilitation, disability support, psychosocial care, help returning to work, assistance navigating the NDIS or Centrelink, and ongoing support for carers and families. Cognitive impairment can make completing applications, remembering appointments and managing multiple services extremely difficult without hands-on assistance.

Brain cancer is not only a survival issue. It is a lifelong neurological, disability and support issue for many of the people who survive.

Sources: Cancer Australia, *Brain cancer in Australia statistics* (2025); Australian Institute of Health and Welfare, *Cancer data in Australia* (2025); Cancer Australia, *Statistics for children's cancer*; Australian Government Department of Health, brain cancer research publications; National Road Safety Data Hub, *Monthly road deaths* (2025 calendar year); Australian Brain Tumour Collaborative, *Navigating the Unknown: A Call for Nationwide Brain Cancer Care Coordination* (2024); Mayo SJ et al., "Cognitive Symptoms Across Diverse Cancers", *JAMA Network Open* (2024).

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THE SIMPLEST WAY TO STRUCTURE YOUR CONVERSATION

MY STORY	THE ISSUE	THE ASK
What happened to me or my family?	What problem or gap did that experience reveal?	What do I want my MP to support or raise?

IF YOU REMEMBER ONLY ONE THING...

You do not need to be a policy expert.

BTAA and the Australian Brain Tumour Collaborative provide the evidence and shared priorities. You bring the lived experience that makes those issues real.

THE THREE ASKS

RESEARCH & TRIALS	**Co-design the next phase of the Brain Cancer Research & Trials Roadmap and $50m MRFF investment priorities.**
CLINICAL CARE	**Fund a National Brain Tumour Navigator Program, aligned with the national cancer navigation system.**
SUPPORT SERVICES	**Co-fund the NAS: $725,000 per year for three years, alongside sector and partner investment.**

One story. One issue. One clear ask.