



BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.

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**AUSTRALIA'S VOICE FOR
BRAIN TUMOUR SUPPORT
AND ADVOCACY.**

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EMPOWERING PATIENTS

GBM patient Rowena Basley and her family support team at the recent COGNO Patient Forum

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The Australian Brain Cancer Landscape 2025

A National Blueprint for Change

By Craig Cardinal

Brain cancer remains one of the most devastating and complex diseases faced by Australians. Though classified as a less common cancer by incidence, its impact is disproportionately severe — it takes more lives of children and young adults than any other cancer, and imposes enormous physical, psychological, social and economic burdens on patients, families, carers and the health system. Despite these realities, brain cancer continues to receive far less funding and structural support than cancers with far higher survival rates.

To change this, Brain Tumour Alliance Australia (BTAA), supported by the Australian Brain Tumour Collaborative (ABTC), has developed the Australian Brain Cancer Landscape 2025. This landmark document is the first attempt to present a coordinated national picture of brain cancer research, clinical care, and support needs. Its objective is simple yet profound: to reset government and community understanding of brain cancer, unite the voice of patients and advocates, and map a clear, evidence-based pathway for action and equity.

At the heart of this Landscape are three interdependent pillars:

1. **Research & Trials**
2. **Clinical Care**
3. **Supports**

Each pillar is essential. Each addresses a critical gap. And together, they form a unified national strategy that could finally deliver the breakthroughs and hope brain cancer patients deserve.

Research & Trials: From Discovery to Delivery

The first pillar builds on the legacy of the Australian Brain Cancer Mission (ABCM 1.0), launched in 2017 as the largest pooled investment in brain cancer research in Australian history. It mobilised \$136 million and brought unprecedented improvements in trial access, infrastructure, and research capacity. Yet, despite these gains, survival rates remain largely unchanged — underscoring the urgent need for a reset.

The proposed ABCM 2.0 calls for a new co-designed mission between government, philanthropy, researchers, clinicians, and the community. Its goals are ambitious yet realistic:

- Create a National Research & Trials Roadmap, spanning discovery science to survivorship research.
- Balance high-risk discovery projects with translational

and survivorship research to ensure a robust “lab-to-patient” pipeline.

- Grow and protect the research workforce, while embedding consumer voices at every stage.
- Drive multinational and multidisciplinary collaboration to accelerate innovation.

In short, ABCM 2.0 aims to transform the groundwork of the past decade into real breakthroughs in survival and quality of life.

Clinical Care: Dedicated Brain Cancer Care Coordinators

For patients and families, navigating brain cancer is often overwhelming. Multiple specialists, fragmented supports, and variable access (especially in regional and rural areas) leave many struggling to find the right care at the right time. Families carry not only emotional strain, but also enormous logistical and financial burdens.

The Brain Cancer Care Coordinator (BCCC) Framework offers a solution. Informed by the BRAINS Program and other evidence-based models, the framework proposes a national network of specialist care coordinators, embedded in multidisciplinary teams, who support patients across the entire disease trajectory — from diagnosis and treatment to survivorship, recurrence and palliative care.

Key elements include:

- Early needs assessments for patients and carers.
- Navigation across complex systems, including rehabilitation and psychosocial supports.
- Hub-and-satellite access, combining metro centres with telehealth and outreach for regional equity.
- National governance, training, and evaluation to ensure consistency and sustainability.

By reducing fragmentation, easing carer burden, and preventing costly hospital readmissions, a national BCCC framework would not only improve outcomes but also generate system-wide efficiencies.

Supports: A National Advocacy Service

Finally, no cancer journey is faced in isolation. For brain cancer, the absence of a government-funded, national support service has left thousands of patients and families to navigate alone.

The National Brain Cancer Advocacy Service (NAS), delivered by Peace of Mind Foundation and funded by Cure Brain Cancer Foundation, has already proven what is possible. Since 2021, it has supported more than 3,000 families, provided navigation and psychosocial support, and become a trusted referral pathway for clinicians across 180 hospitals.

NAS is unique in its consumer-led, national model. It provides personalised one-to-one support, crisis response, navigation of complex health and social systems, linkage to trials, and policy representation to ensure lived experience informs decisions.

The ask of government is modest but critical:

- Fund eight FTE specialist staff (\$1.175M annually) to secure national coverage.
- Formally integrate NAS into cancer navigation programs and referral pathways.
- Recognise NAS as the national peak consumer support service for brain cancer.

By bridging the gap between diagnosis and the healthcare system, NAS relieves pressure on hospitals, reduces trauma and isolation, and provides families with the scaffolding they need to survive the journey.



A Call to Action

Brain cancer devastates lives — but change is possible. The Australian Brain Cancer Landscape 2025 is not just a document; it is a blueprint for national action. By advancing Research & Trials, Clinical Care, and Supports together, government has the opportunity to deliver breakthroughs, equity, and hope to Australians living with brain cancer.

As the BTAA and ABTC emphasise, the time for fragmented responses has passed. What is needed now is coordinated investment and recognition of brain cancer as the national priority it is. Patients and families cannot wait another decade.

BTAA's Australian Brain Cancer Landscape 2025 document will be officially launched and presented to government at the 2025 Head to the Hill event.

Craig



Craig Cardinal
Chair

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

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

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

COVER STORY



Empowering Patients: Highlights from the BTAA Patient Education and Information Forum

Held on Sunday 14 September alongside the COGNO Annual Scientific Meeting, the BTAA Patient Education and Information Forum brought together over 80 patients, carers, and family members for a day of insight, connection, and shared experience.

Co-hosted by The Brain Cancer Group and the Brain Tumour Alliance Australia (BTAA), the forum offered a unique opportunity for attendees to hear directly from some of the world's leading brain cancer experts. The program featured presentations from distinguished speakers including A/Prof Karin Pill, Prof Haryana Dhillon, Dr Angela Mweempwa, and Dr Wade Pullin, covering a range of topics from cutting-edge glioma trials and rare central nervous system tumours, to supportive care strategies and practical guidance for those navigating a brain tumour diagnosis.



Marina Kastelan, Prof. Haryana Dhillon, A/Prof Karin Pill (Denmark), Dr Angela Mweempwa (NZ), Siew Koh (COGNO Chair), Christine Whittall (BTAA) at the COGNO patient forum



The Brain Cancer Group



Kirsty Sinclair and Debra Balhatchet, brain tumour survivors.



GBM patient Rowena Basley and her family support team.



Ann Baxendine and Jillian Churchill, brain tumour survivors and carers.



The question and answer forums, and the patient and carer group sessions, allowed participants to discuss their own experiences and solutions in a supportive environment.

This annual forum continues to be a cornerstone event on the brain tumour community calendar, not only for the valuable medical updates it provides but also for the sense of community it fosters. For many, it's a chance to share stories, ask questions, and connect with others facing similar challenges.

If you were unable to attend, recordings of the forum presentations are available online. Visit the 'Resources and Support' section of the BTAA website to access these valuable sessions.



Susanne and Stuart Remphrey, co-carers and patients.

Introducing myself: health policy specialist, brain cancer patient, brain cancer survivor, Executive Officer of BTAA

Christine Whittall

I was in treatment when I reached out to BTAA for the first time to see if there was something I could do to support their work. Having worked in health policy and advocacy for my entire career, I knew that patient experience was important in shaping the work of health non-profit organisations.

Having worked in health non-profit organisations for most of that career, I also knew that being trained in advocacy and having experience working with evidence is crucial in securing real change for patients, care givers and clinicians.

Happily (or unhappily?), I have both the expertise and the experience.

How did I get here: Executive Officer of BTAA

My brain cancer journey started last year when, after a seizure, I was diagnosed with a Grade 2 Oligodendroglioma. Some months, two craniotomies, 30 sessions of radiation and I-lost-track-of-how-many rounds of chemotherapy later, I reached out to BTAA with a subject line of "Would like to be involved".



But really, the journey started 20 years ago when I was training in medical research and public health. My career took me through several roles in different health non-profits focused on everything from type 1 diabetes to global health.

One of the pivotal points in my career was at Cancer Council Australia where I was responsible for public health policy. The focus of the role was cancer prevention and screening. I knew everything there was to know about breast, cervical, bowel, and skin cancer. And next to nothing about brain cancer – you can't prevent it, and we don't screen for it.

I also worked in NSW Health for several years, to gain a better understanding of how government works, how decisions are made and policies set. That experience took me back to the non-profit sector – specifically to an organisation whose mission was something along the lines of "better use of evidence in policy and practice".



Christine Whittall, Executive Officer of BTAA

Why BTAA?

After taking a break from my career following diagnosis and treatment, I am ready to get back to work. There is significant work to be done for this community and BTAA is uniquely placed to do it.

Australia has a number of outstanding non-profit organisations working in this space – raising awareness, funding research, educating patients and clinicians, and providing resources to people facing diagnosis and treatment. What makes BTAA different is its breadth and its roots.

BTAA has always been powered by volunteers, every one of them with a personal connection to brain cancer. They represent the community because they are the community.

Established in 2008, BTAA is a national voice, supporting everyone in this community regardless of age, tumour type and location, while advocating across the full spectrum of issues: support, clinical care, and research.

Their reputation speaks for itself. When I first considered becoming involved, I asked my oncologists about BTAA. The response was unanimous: yes, they knew the organisation, and yes, it was highly respected.

BTAA were also there when I needed them. I joined the Sydney support group while I was still in treatment. The understanding and solidarity I found there was invaluable. That experience of being supported, and being able to give support in return, reinforced how vital BTAA is.

Finally, their work aligns with my professional background – affecting system wide, evidence-based change that delivers real benefits for people. In BTAA, I see the chance to bring that experience to a cause that is both personal and urgent.

What does an Executive Officer do?

Executive Officer sounds like a big title, but in a small organisation like BTAA it means wearing many hats. My job is to keep the organisation running smoothly day to day, while also helping shape where we're heading.

It's part leadership, part problem-solving, part coordination, and sometimes just rolling up sleeves to get the work done. In practice, that might mean one day I'm preparing reports so decisions are well-informed and transparent. Other days it's following up projects, making sure deadlines are met and nothing slips through the cracks. It might mean meeting with health professionals or government to push for better support, or working with volunteers to get make sure events run like they should.

But the part of the job I love best so far is what the position description might call "stakeholder engagement". What I call it is: connecting with the patients and carers to hear your stories, educating clinicians on the realities of living with brain cancer and its treatment, talking to the amazing organisations who are active in this space about how we can amplify each other's voices, and advocating for this community and strengthening your voice to decision makers in government, to ensure that brain cancer is a priority.

I hope I get the opportunity to meet lots of you while I am in this role.

Are you interested in volunteering for BTAA?

BTAA will always be strongly connected to the brain tumour community and rely on volunteers to deliver on our mission. If you'd like to get involved, there are many ways to help. Your time, skills, and lived experience all make a difference.

To learn more, get in touch with us at enquiries@btaa.org.au I would love to hear from you.

The BTAA Lynette William Award at the Co-operative Trials Group for Neuro-Oncology (COGNO) Annual Scientific Meeting

From 14–16 September 2025, the 17th COGNO Annual Scientific Meeting gathered neuro-oncology experts at the Langham Hotel, Gold Coast, Queensland. Under the theme "New Horizons, Novel Therapies", the conference showcased the latest in brain-cancer clinical trials of novel therapies, advances in imaging and surgery, translational science, and new approaches to supportive care.

With more than 200 delegates, this was the largest COGNO meeting yet, bringing together clinicians, scientists, allied health staff across many disciplines, along with consumer advocates in a united effort to improve outcomes for people with brain tumours.

BTAA champions supportive care research at the COGNO meeting, through the BTAA Lynette Williams Award. This year's recipients were:

Best Supportive Care – oral presentation

Dr. Carrie-Anne Ng - Reaching consensus on a core patient-reported outcome set for brain cancer clinical trials in Australia and New Zealand

Best Supportive Care – poster presentation

Dianne Legge - Co-designing ICONIC: a communication skills training resource with and for healthcare professionals in neuro-oncology.



Exploring Wellbeing After Cancer: Why Teenagers' Voices Matter

Every year in Australia, about 2,000 people under 25 are diagnosed with cancer, many with brain and central nervous system tumours.¹² Thanks to advances in care, most young people respond to treatment and survival rates are high,¹² but finishing treatment doesn't always mean life returns to normal.

For teenagers aged 15–19 who have been treated for cancer, recovery can disrupt an important period of developing independence, identity, and friendships. Some young people face lasting health issues (for example, heart, kidney or liver problems, infertility, or diabetes). Others experience fatigue, changes in memory or concentration, or social setbacks after time away from school.

These effects can delay milestones such as finishing high school, starting work or university, and forming relationships. Some may need to study part-time and miss graduating with their friends, or delay their first job and need to rely on their parents for longer. Follow-up care can also be difficult to navigate, especially when moving from children's services to adult healthcare.

Why We Need Teenagers' Perspectives

Health professionals know teenagers have distinct needs, but research has rarely captured their voices. Statistics can describe survival and cancer types; they can't explain what everyday life feels like after treatment. Many studies also group the experiences of broad age ranges together, from toddlers to adults, making it hard to identify the specific needs of 15–19-year-olds.

Important questions, such as what 'being well' means to young people, what support they really value, and how they manage lasting side-effects, are best answered by teenagers themselves and their families.

About the 'Exploring Wellbeing in Young People Treated for Cancer' Study

Researchers at the University of Queensland are running the Exploring Wellbeing in Young People Treated for Cancer project to address these gaps. We're conducting confidential, one-to-one Zoom interviews with teenagers who have completed cancer treatment and with parents or guardians. Insights from these conversations will help shape more age-appropriate follow-up care and ensure teenagers' voices are heard.

An Invitation to Take Part

If you are aged 15–19 and have been treated for cancer, or if you are a parent or guardian of someone in this group, we would love to hear from you. By sharing your experiences, you can help improve support services for others. To get in touch, please scan the QR code or email sarah.walker1@uq.edu.au.

About the Researchers

The project is part of a PhD being undertaken by Sarah Walker at the University of Queensland. Sarah is a cancer nurse with over 20 years' experience supporting adolescents. She is supervised by Dr Jemma Venables, Dr Stefanie Plage and Dr Amy Mitchell, who bring expertise in adolescent health, cancer treatment, and wellbeing support.

References

1. Australian Institute of Health and Welfare (AIHW). *Australia's children*. Canberra: AIHW; 2022.
2. Australian Institute of Health and Welfare (AIHW). *Cancer in adolescents and young adults in Australia 2023*. Canberra: AIHW; 2023.



BTAA SPECIAL EVENT

Head to the Hill 2025

Your Chance to Raise Awareness of Brain Tumours



Tuesday, 28 October 2025

8:30am – 12:00pm

Parliament House, Canberra



SCAN TO RSVP!

All attendees must present valid photo ID (driver's licence or similar) to gain access to Parliament House.

Join us in Canberra for Head to the Hill 2025, our third annual gathering at Parliament House, as we continue to shine a spotlight on the devastating impact of brain tumours in Australia.

This important advocacy event brings together patients, families, carers, clinicians, and researchers to call for urgent action to address the unacceptable and largely unchanged survival outcomes for people diagnosed with brain tumours. Together, we will share powerful stories and highlight the profound financial, social, cognitive, emotional, and physical toll brain tumours inflict—not just on individuals, but on entire communities.



A Powerful Visual Tribute

A striking visual display will form the centrepiece of this year's event: more than 2,000 pairs of shoes placed along the Parliament House courtyard pathways. Each pair symbolises a life affected by a brain tumour, powerfully illustrating that this disease does not discriminate—touching Australians of all ages, genders, and backgrounds.



Engage with Policymakers

We've invited Federal Members and Senators to join us in the courtyard to hear directly from those affected by brain tumours. For those attending in person, this is a unique opportunity to speak face-to-face with Parliamentarians and advocate for meaningful change in research funding, treatment options, and support services.

Writing is my life-line

On navigating illness with words

By Kate Bown

When I was ill I kept a diary. I wrote a little everyday in a red leather-bound notebook. In the beginning, my writing was large and scrawly, like a child's. Perhaps, my pen was running away from my illness, or it was just hard to focus on the unlined pages. Brain surgery had left me with double vision and an eye patch had become my favourite accessory.

Sometimes I wrote about what was worrying me, and other times a dot by dot account of what I ate through the night —

12th February 2013

I woke feeling so weak and hungry I couldn't go back to sleep. I chewed on my white bed sheet, thinking it was a piece of toast.

Sometimes I wrote letters to friends, and they would reply with quirky cards and stickers left over from their traveling days. I remember running my fingers over the envelopes, feeling the grooves and bumps on the paper like braille, their words hanging in my ears like tiny jewels.

Writing gave me a way to connect with the people that I loved when my energy was low and my sutured head was still so sensitive to the world.

One day my sister-in-law sent me a beautiful card. On the front was a quote —

'In the midst of winter, I finally found that there was in me an invincible summer.'

I wrote it many times in my diary. The words seemed to lift me, on my hardest of days. But mostly, I wrote it because I wanted to believe that it was true. I wanted to believe that my time wasn't up, that I would endure.

*

There is something powerful about putting an experience into language — committing words to tongue, story to pen and paper.

When I write I can feel the words rising like a hot flush under my skin, trembling in the air, willing me to believe.

I wonder if we could launch love around the world with this energy, stop the glaciers melting, grow our trees fat and tall, find a cure for brain cancer?

This is not to say that language is always a positive force. It can mislead, mistreat, destroy and divide, just as easily. But what all stories have in common is their impact on us.

And I'm thinking of the opening line of the poem *Sway*, by Ada Limón:



What is it about words that make the world fit easier? Air and time.

For language is breath passing through the body, squashed by gravity, sucked into the ear of another. And it is also an exchange, reminding us that we are not alone, that illness and loss, joy and love, are universal conditions experienced as a community.

*

In 2015, Australian writer Georgia Blaine collapsed in her garden, blood frothing from her mouth. She had suffered a seizure and was rushed to hospital. Later she was diagnosed with brain cancer. A tumour was growing in the language centre of her brain.

Georgia was given a bleak prognosis. She wrote about her illness in a column for the *Saturday Paper* entitled *The Unwelcome Guest*, and in her memoir *The Museum of Words*, a memoir of language, writing and mortality. Throughout her illness, writing was her way of holding onto life.

'Time and time again, writing is my lifeline, the rope that I use, inch by inch, word by word. It is the way in which I forget myself, even though I am writing about myself. Some days, I feel it is the means by which I am keeping myself alive, escaping the death sentence of this illness for another day.'

In December 2016, just 13 months after her diagnosis and two days before her 50th birthday, Georgia died, leaving behind a husband and daughter, friends and family, and her words — novels, essays, memoirs, and short stories.

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Story continued on page 12...

Peter's story

Pat and Pete Wynn

31 August 1988 – the day that changed life as we knew it.

Thirty seven Years of Brain Cancer.

37 years ago, I returned to the Shell Depot in Fyshwick ACT after driving a petrol tanker. I remember speaking to a co-worker, but apparently, I wasn't making much sense. I drove home and that's the last thing I remember until I woke up in Canberra hospital.

Apparently, I walked in through the back door and said some things that really didn't make a lot of sense, crouched down, pointed and started spinning around the room.

Our two-and-a-half-year-old son and one year old daughter were asleep on the lounge. My brother and sister-in-law were visiting at the time and watched in shock as I crashed into a metal bin, which held wood for the fire, and fell to the floor into what we now know was a grand mal seizure. The seizure lasted for several minutes. My wife says she thought I was having a stroke.



Pete at the time of diagnosis'

After a CT scan and MRI I was diagnosed with a brain tumour. It was graded 2-3 mixed Oligodendroglioma and about the size of a small orange in the right temporal lobe. I had surgery in early September 1988. Life as we knew it was over. After 2 weeks in hospital, 6 weeks of Radiotherapy and several more weeks of recovery I went back to work but not to the driving job that I loved. I was to be retrained in the office. That was ok in theory, however I had just had major brain surgery, I was tired all the time and just wanted to sleep. I was frustrated at the retraining as my short-term memory was shot. I was made redundant from that position about 12 months later. I was relieved but also lost as I couldn't do the job I loved. Back in those days the driving restrictions weren't as conservative or strict as they are now.

Within a few weeks I had another job driving for another company delivering, initially, gas cylinders and then driving gas tankers all over NSW and ACT. In 1996 I had a seizure and was eventually made redundant from that position as well. A series of jobs both driving and mechanical over the next 10 years followed. Eventually I was able to get back to driving trucks which I was happy with.

In 2004, 16 years later and another son later, a recurrence was discovered on an MRI. We had started to get a bit slack with the annual checkups and we think I had gone at least 2 years between the last clear MRI and the one with a recurrence. We had started to notice a few things that made us get the test done, falling asleep at the wheel being one of them. Falling asleep at the drop of a hat being another. No seizures. Another resection by Dr Chandran, a slightly higher-grade tumour, of a similar type. It was after this surgery that we were told that this would be how life was now. I would get more tumours and they would eventually kill me. Up to that point we had no idea that this was a possibility. In hindsight perhaps we just weren't listening.

At the time of my first surgery there was no treatment other than surgery and radiotherapy. Radiotherapy wasn't an option again but thankfully there was now Temozolomide. Six months of chemo treatment followed and another redundancy as I once again was not allowed to drive trucks or any vehicle.

By 2014 I started having funny little episodes, with no sign of anything in between, I had managed to get myself into another job driving trucks. The episodes were focal seizures. Thankfully I was with a major company which worked hard to keep me in a job. They tried to retrain me in an office job, which I truly hated. The focal seizures turned out to be from residual damage from the radiation therapy. No tumour this time.

However, in addition to the Dilantin I had been taking for the past 26 years I started taking Kepra to control the seizures. This drug turned out to be great at controlling the seizures but increased the fatigue and I felt like I was in a bit of fog. I struggled to process tasks and learning a new job was almost impossible. I would have to ask time and time again for direction and couldn't remember what was being said. My short-term memory is really quite bad.

Twelve months later I started having focal seizures frequently, so another trip to the hospital and within 24 hours a small tumour had been discovered on an MRI, despite a clear one 6 months earlier. A recurrence in the same place, although caught very early and measured only 5mm and a lower grade than the 2004 tumour.

The dose of Kepra was doubled and so did the side effects. Another surgery, 5 days in hospital, and a 10-year suspension of the truck driving licence. I was once again made redundant.

I have had to accept that truck driving is now a thing of the past. Since the last surgery in August 2015, I have been unable to return to work, due to being unable to work quickly enough or stay focused on what I need to be doing. I get frustrated and have trouble with motivation.

Over the years my medications have been modified although I still have pretty regular focal seizures which means two more anti-seizure medications. Fatigue is constant. Lack of motivation is something else I have trouble with. The TV is my main form of entertainment.

A couple of years ago the radiologists thought there may be a recurrence but if it is, it is extremely slow growing and for the moment we are on wait and watch.

Brain tumours are not always a death sentence, but they are life changing for me and my family. As my wife still works full time, I am not eligible for any pensions, although I have been fortunate enough to get NDIS which offers some assistance.

Pat and Pete Wynn

Pat is the long serving BTAA Treasurer, and Pete is an active BTAA member.



Pete now



By Kate Bown

Continued from page 12...

Two years ago, just before the tenth anniversary of my diagnosis, I wrote a story about my brain tumour journey. I wrote about the passing of time and the gifts of surviving, what it means to love, and the importance of wild places for healing.

I am not an accomplished writer by any means, but by writing this story I had discovered what mattered most in my life.

Why ten years, I hear you ask? Perhaps, I had needed the time to reflect on what I had learnt, or to write uninterrupted — away from four children, on a computer, in full sentences.

As I look back at this story, and the other writing I have shared about my illness, I feel awkward, afraid even. I can see the edges of myself. And I notice things I would have written differently now. Perhaps, time has a role to play. After all, our stories reflect where we are in our lives.

But this is not the only story I want to write.

There are others, jostling for space on the page. And I want to escape that familiar illness narrative arc — fall ill, battle like a hero, recover, be at peace with your journey, and share what you have learned.

I'm ready to write the next chapter of my life because I have found the thing that makes me want to live a little longer, love a little harder. A line to grab onto and wrap around my life, holding it close, so I can see just how gorgeous it is.

*

And you?

Do you have a story to share?

If this article has raised concerns for you, please call your local mental health team or if in Australia contact Lifeline 13 11 14 or www.lifeline.org.au. If you feel in immediate danger please go to your local hospital.

Feeling Prepared, Not Alone: Bringing Early Cognitive Support into Brain Tumour Care

Sophie Reed Registered Neuropsychologist and PhD candidate

Up to 90% of people with a brain tumour experience cognitive challenges, regardless of whether the tumour is benign or malignant, high grade or low grade, or located in the frontal lobe or brain stem. These challenges can have a huge impact on day to day living and quality of life, as cognition, or our 'thinking skills', underpin so much of what we do, often without us even realising it. It affects how we concentrate on a pesky project at work, how we find the words to join a conversation, and how we make and hold onto our most cherished memories. For carers, these changes can be equally challenging. **Watching a loved one struggle to remember, find words, or manage daily tasks can bring its own stress, sadness, and need for adjustment.**

Despite there being such a high rate of cognitive difficulties in people with brain tumours, there is still very little offered in terms of support. In the early stages of my PhD, I searched everywhere from Google to government websites and cancer forums, and what I found was countless brochures and stacks of information sheets offering generic advice. Tips like "do more crosswords to keep the mind sharp" felt far removed from the reality of living with a brain tumour. It was baffling to me, that the same advice could be given to someone with a tumour affecting memory and language (such as in the left temporal lobe) and someone with a tumour affecting sensation and spatial awareness (such as in the right parietal lobe). Clearly, I thought, a one-size-fits-all approach to cognition is not enough.

Even when I did find excellent tailored cognitive rehabilitation programs, I noticed that they usually start after treatment, when people are trying to return to "normal" life. What seemed to be missing was something offered earlier, before treatments such as surgery, chemotherapy, or radiotherapy begin, which can all impact thinking and memory. This led me to ask a simple but important question: What if, instead of waiting for cognitive problems to arise, we helped patients and caregivers prepare for them in advance? In the same way that people strengthen their muscles before hip surgery, or take anti-nausea medication before chemotherapy, can we help families anticipate potential challenges and feel more equipped to manage them if they do arise?

This idea of cognitive 'pre'habilitation is the focus of my PhD. Together with my wonderful team of neuropsychologists (pictured), we are hoping to develop an intervention that takes place before surgery or adjuvant treatment to:

1. Explain how the tumour's location and treatment might affect thinking and memory
2. Offer personalised strategies to manage potential difficulties
3. Provide early information on where to turn for support if challenges arise



Dr Vincent Oxenham; Kathleen Rolfe; Sophie Reed; A/Prof Heather Francis

We hope that by doing this, we can move away from the "learn as you go" experience that so many patients and families face. Instead, we will provide a proactive approach that helps people feel more prepared, supported, and confident about the journey ahead.

Neuropsychologists are experts in the relationship between the brain and behaviour. This means we can often predict how changes in the brain may affect thinking, memory, emotions and behaviour. Through cognitive testing, we can test these predictions and identify patterns of strengths and weaknesses in different cognitive functions that can guide rehabilitation and practical support.

Our approach is holistic and person-centred. We consider not only the effect of the tumour and its treatments, but also factors like fatigue, mood, and wellbeing, all of which can shape how cognitively "sharp" someone feels. Most importantly, we tailor our work to the individual, acknowledging that everyone's brain, and everyone's life, is unique. For someone who has always functioned at a very high level, even small changes may feel overwhelming, while others may be less affected by similar challenges. Recognising these differences is at the heart of what we do.

Unfortunately, despite this expertise, neuropsychologists are not yet a routine part of brain tumour care, meaning many patients and families miss out on support that could make a real difference. Part of my research is about demonstrating why this kind of support should be built into care from the very beginning.

If you are interested in our work or would like to take part in our research, we would love to hear from you. We are currently inviting patients and caregivers to share their experiences and ideas about what could have better prepared them for surgery and beyond.

Sophie Reed Registered Neuropsychologist and PhD candidate
sophie.reed@hdr.mq.edu.au

On a final note, the brain tumour community is one of the most kind, resilient, and generous groups of people I have ever met. It is an honour to carry out this research alongside you and on your behalf. It is a privilege I will never take lightly.

“Let Me Know How I Can Help”

By Pam Hubner

When someone receives a brain cancer diagnosis, it's natural for those around them to want to help. One of the most common things people say is, “Let me know how I can help.”

I remember clearly hearing those words myself—spoken by a young woman named Angie, from the central Queensland town of Emerald, shortly after my own daughter, also named Angie, was diagnosed.

That simple question, asked with such sincerity—“How can I help?”—warmed my heart and gave me comfort in a very uncertain time.

At the time, I was living in Brisbane, while my daughter was in Emerald. I'd once lived there too and still had a network of long-time friends in the area. I knew some of them would want to support us, but even with a solid community, navigating offers of help can be overwhelming.

It's important to remember that some people have large families or support circles, and others have very few. Every situation is different. But what remains true across the board is this: practical, thoughtful support can make a world of difference.

Create a Helping Roster

If multiple people are offering help, a great way to manage support is to create a roster. For us, especially in the final months, meal support was vital—and a roster helped us stay organised without overwhelming anyone. Not every idea will suit every person or situation, but here are some suggestions based on what worked for us and other families I know.

Practical Help Around the House

Sometimes it's the smallest things that bring the greatest relief. Offering help with:

- Mowing the lawn
- Vacuuming, mopping, or dusting
- Grocery shopping
- Laundry
- Taking out the bins

These everyday tasks can become burdensome for families focused on medical appointments, treatment, and emotional survival.

Meal Support

Meal preparation is a major stressor, especially on long days filled with appointments or when fatigue is high.

You can help by:

- Dropping off cooked or prepared meals
- Baking treats for the kids
- Offering food vouchers or organising home delivery
- Preparing freezer-friendly meals for later use
- Tip: Avoid dropping by unexpectedly. A quick text or call to check timing is always appreciated.

Childcare & Family Support

Children may not fully understand what's happening, but they can still feel the stress in the home. Helping out can mean:

- Babysitting for a few hours
- Taking kids out for the day or for a sleepover
- Organising a date night or weekend away for the parents

Maintaining routines for children can be comforting during uncertain times.

Administrative Help

If you or someone in your circle has experience with:

- Centrelink
- NDIS
- Navigating medical referrals or government forms

...your skills can be an absolute godsend. Many carers are overwhelmed by paperwork on top of everything else.

Pet Care

Pets are family too. Help by:

- Walking the dog
- Taking pets to vet appointments
- Providing temporary care if needed

Transport

Often, patients lose their driver's licence for a period, or just don't feel confident driving. You can:

- Drive them to appointments
- Take them shopping
- Offer lifts for the kids to and from school or sport
- Plan a special outing—coffee at a favourite café or even a quiet beach trip

Remember, the journey itself can be a break from routine and a form of therapy.

Thoughtful Gestures

Small, thoughtful gifts can bring comfort and joy:

- A voucher for a massage or hair appointment
- A care basket (lip balm, eye mask, hand cream, meditation audio, soft music)
- Flowers, a favourite drink, or a handwritten note
- A small toy or book for younger children
- A fruit basket
- A favourite book or puzzle
- A surprise lunch with old friends (my daughter loved this)

Note: Avoid offering medical advice or “miracle cures.” Just being present and supportive is enough.

Emotional Support

Perhaps the most important support of all is emotional. Here's what can help:

- Be a good listener
- Let them lead the conversation
- Avoid probing questions
- Sometimes, just being there—watching TV or reading a book side by side—is enough
- A gentle touch can speak volumes when words fall short

Encouragement & Support Groups

Encourage your loved one to connect with others by joining a local or online support group. Offer to attend with them, especially the first time. It can help to meet others walking a similar path.

Acknowledge Their Emotions

Let them know it's okay to feel overwhelmed. A simple, “It must be so hard right now,” can be more powerful than trying to find the right words to fix it.

Respect Their Routines

In our case, my daughter wanted to maintain her children's routine as normally as possible for as long as she could. This gave her a sense of control and normalcy. Be sensitive around children—don't speak about the illness if they're not aware of it.

Always check in about boundaries with both the patient and the carer. Everyone handles things differently.

Offer Distractions

Sometimes, talking about anything but the illness is exactly what someone needs. Share funny stories, talk about everyday things, or just enjoy a movie together. Distraction can be a form of therapy too.

Be Patient

People facing brain cancer may be irritable or withdrawn. They are dealing not just with physical illness, but also with medications, fatigue, and the emotional weight of the diagnosis. Sometimes the tumour itself affects mood and behaviour.

Meet them where they are—with patience, not judgement.

A Final Thought

My experience won't be the same as everyone else's. But the most important lesson I've learned is this: make sure they feel loved, valued, and heard.

Sometimes we won't have the right words—but our presence, our actions, and our quiet support will speak louder than anything we can say.

We can't fully understand what they're feeling—but we can sit beside them through it.

Pam Hubner is a mother who supported her daughter through a brain cancer diagnosis and treatment. She shares her story in the hope that it helps others navigate the difficult, beautiful, and heartbreaking moments of the journey.





NEED SUPPORT NOW?

PHONE 1800 857 221



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

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

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

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

Email btaa@shout.org.au

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