



Navigating The Unknown

A CALL FOR NATIONWIDE BRAIN
CANCER CARE COORDINATION



NOVEMBER 2024



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About ABTC

The Australian Brain Tumour Collaborative (ABTC) was established in December 2022 to nationally advocate for brain cancer patients, their families and their carers. The ABTC seeks changes in government policy and action to minimise the significant challenges faced by patients, their families and carers from date of diagnosis and throughout the survivorship journey.

The Collaborative's objectives are as follows:

- Identify and promote **understanding of key gaps in services** and support for people impacted by brain tumours.
- Promote **integration, partnerships and information sharing** within the national brain tumour sector that better supports people impacted by brain tumours.
- 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.
- Individually and collectively advocate for **better access to service coordination and ongoing supports** for people with brain tumours, their families and carers.
- Continued **funding for research and clinical trials** to enable and accelerate better prevention, treatment and care.

The ABTC recognises and supports the individual objectives and achievements of all Australian brain tumour support providers and stakeholders, and seeks the enhancement of current critical initiatives, such as the Australian Brain Cancer Mission.

The Collaborative's nine founding member organisations are:



About this report

The ABTC hosted a roundtable that was convened on Tuesday, 29 October 2024. The event was facilitated by Evohealth and involved key stakeholders from clinical research, patient advocacy and allied health backgrounds.

The aim of the roundtable was to discuss gaps in cancer care navigation faced by brain cancer patients, their families and carers in Australia.

This report is informed by the insights shared by stakeholders at the roundtable, and enhanced with the results of a survey of brain cancer care coordinators across Australia, and selected

submissions received from people with brain cancer, and their loved ones.

We would like to acknowledge the individuals who contributed to this project, particularly the attendees of the roundtable and the tireless work they do for the brain cancer community.

ABTC roundtable attendees

- **BILLIE LOGAN** | Paediatric Neuro-oncology Nurse Consultant, Adelaide
- **CARLY SMITH** | Cancer Nurse Coordinator Head Neck Brain, Brisbane
- **CRAIG CARDINAL** | Chair ABTC, Brisbane
- **FIONA HASSMANN** | Manager National Advocacy Service, Gold Coast
- **GINTA ORCHARD** | Executive Officer Adelaide Brain Cancer Support Group, Adelaide
- **GRACE SINCLAIR** | Neuro-oncology Cancer Nurse Coordinator, Melbourne
- **A/PROF HARYANA DHILLON** | Lead Investigator BRAINS Program, Sydney
- **JANINE GILMOUR** | Senior Social Worker Oncology, Western Australia
- **DR KIM WARK** | Head of Research Robert Connor Dawes Foundation, Melbourne
- **LEBOGANG THOMY** | Clinical Nurse Consultant Brain, Renal and Bladder, Brisbane
- **MARCIA FLEET** | Cancer Nurse Coordinator, Melbourne
- **DR MEGAN JEON** | Postdoctoral Researcher BRAINS Program, Sydney
- **NGIARE PARKYN** | Brain Cancer Specialist Nurse Coordinator, Canberra
- **SANDY NIXON** | Brain Cancer Coordinator, Newcastle
- **VICTORIA FREW** | Neuro-oncology Nurse Practitioner, Sydney
- **WIBKE WHILLANS** | Brain Tumour Support Officer, Melbourne

The complexity of brain cancer

Every Australian diagnosed with brain cancer faces a completely unique journey.

Each year, approximately 2,000 Australian babies, children and adults are diagnosed with more than 100 different types of brain cancer.[1] The type of brain tumour and onset varies with age, resulting in vastly different experiences for patients when it comes to symptoms, available treatments, and prognoses. Limited research funding has hindered progress for Australians with brain cancer, which has historically received less than five per cent of all Commonwealth cancer research funding.[2]

Five-year survival rates are only 23 per cent and have improved by just two per cent over 30 years.[3,4] Survival statistics vary dramatically for different tumour types, falling to less than

six per cent for those with glioblastoma, which accounts for 65 per cent of diagnosed adult brain cancers.[5] In contrast, the five-year survival rate for all cancers was 71 per cent in 2020.[6]

Brain cancer outcomes are worse for children, representing 40 per cent of cancer deaths for children aged 0–14 years.[7] With a 55 per cent survival rate in children under five, brain cancer is the leading cause of death among all childhood diseases, including cancers.[8] Certain tumours are particularly harrowing for children and families; more than 90 per cent of children diagnosed with diffuse midline glioma, for example, will not survive beyond two years.[9]

Five-year survival rates for brain cancer have improved by just two per cent over 30 years.^[3,4]

The disabling challenges of brain cancer

Beyond the physical symptoms of brain cancer, a unique set of neurological, psychological and mental health symptoms make this disease particularly challenging for patients, carers and families. This often includes drastic changes in behaviour, significant deterioration in mental health, and cognitive impairment.[10–12] Symptoms and experiences of brain cancer can change rapidly, leaving those with the disease, their carers and families, unprepared for the uncertainty this brings.[13]

“

All cancer patients face loss of some kind, but the fear of ‘losing your mind’ is quite unique.”

Brain cancer care coordinator, Queensland

The impacts and symptoms of brain cancer invade all aspects of life, becoming more disabling with severity and time. Cognitive impairment restricts how people work, study and live.[14]

Driving becomes progressively unsafe, as seizures, vision changes and other symptoms restrict the ability to work and live a fulfilling life.[15] Personality and behaviour changes result in unexpected outbursts, anger and irritability, affecting relationships with family and friends.[16] Anxiety and depression are common comorbidities, particularly from the constant

unknowns and “scanxiety” endured when waiting for test results.[12] Every patient experiences these changes differently depending on their life stage, tumour type, prognosis and accessible supports. The duration of the cancer journey is also highly variable, from less than a year to well over a decade.[17]

Only 23 per cent of Australians with brain cancer will survive five years or longer.^[5]

There are few treatment options for patients. Standard care is highly invasive, including gross resection of brain tissue and radiation therapy, which can damage healthy brain tissue and create further neurocognitive dysfunction.[18,19] Chemotherapy, where available, is associated with several toxicities.[18] Treatment is emotionally and psychologically challenging, and children often develop anxiety and post-traumatic stress disorder after enduring treatment.[20]

“
When they open your brain, you are never the same [again].”

Australian with brain cancer

The disabling effects of brain tumours are significant and only worsen with time, as patients require additional support services and therapies. The economic consequences of this are poorly understood and there is little to no data available to assist. The costs are likely to be substantial, however, and the National Advocacy Service reports that the average National Disability

Insurance Scheme (NDIS) plan for brain tumour patients is between \$230,000 and \$300,000.[21] This is approximately four to five times greater than the national NDIS plan average of \$58,900 for those who are not in supported independent living.[22]

Together, the neurocognitive, physical, and emotional impacts of brain cancer erode a person’s capabilities and independence. This can hinder their ability to self-advocate and navigate the health system, as they struggle to make decisions, access information, and coordinate their care across several specialities.

Roundtable attendees highlighted that both adolescents and young adults (AYA) and those with long survivorship journeys often fall through gaps in the health system; whether during transitions from paediatric to adult services or through periods of movement in and out of the system during “wait and see” phases. It is no surprise that Australians with brain cancer become reliant upon carers and family members for physical, psychosocial and practical support.

The financial cost of disability support for Australians with brain cancer is 4–5 times greater than the national NDIS plan average.^[21,22]

The impact on carers and family members

Family and carers bear a heavy burden helping their loved ones with brain cancer. They must navigate a constantly changing set of symptoms, needs and behavioural changes, including aggression, irritability, anxiety and depression.^[13] Family, including children, can be traumatised as they watch these changes from the sidelines, with little ability to help.



The impact on our children from watching their once fit and lively father deteriorate both physically and mentally is tough. Our youngest son has panic attacks...our daughter suffers from extreme anxiety.



Family member affected by brain cancer, South Australia

Each caregiving journey varies greatly. It is typically intense from diagnosis, and with escalating care needs throughout, this journey might last two years for some, or extend over 20 years for others. Family carers will also often have to assume additional parenting, household and financial responsibilities.^[23] Though individual experiences vary, a consistent experience is the complex grief accompanying end of life care, which often involves severe burnout, depression, physical exhaustion, and a loss of purpose.^[24]

Furthermore, carers and families also face considerable uncertainty and anxiety associated with identifying support needs and services, managing symptoms, navigating the health system, or in accessing supportive therapies.^[13] The roundtable highlighted how the unique needs of people with brain cancer, coupled with numerous comorbidities and rapidly shifting symptoms, place a significant and often overwhelming burden on carers. Caregivers worry about their ability to provide the right care at the right moment, often becoming anxious and hypervigilant as a result.^[25]

It is incumbent upon government to reshape the landscape of brain cancer support to ensure no one embarks on this complex journey alone.

People with brain cancer need specific care coordination to support their complex needs

Brain cancer care coordinators (BCCCs) are critical to delivering effective, timely and safe care for people with brain cancer and their families.[26] This role, often held by nurses, social workers, neuro-psychologists or occupational therapists, requires advanced clinical and communication skills to navigate the complex situation of brain cancer needs and the Australian health system. Roundtable attendees discussed

the challenging nature of this role, which involves supporting patients, families, and carers across their unique cancer journeys, managing neurocognitive disabilities, psychosocial challenges, changing comorbidities, medication needs, and arranging palliative care. These BCCCs also advocate for their patients in the health system, including within the multidisciplinary team (MDT) to ensure their needs are understood.



What's in a name?

There is no uniformity in the role title, which can further confuse care accessibility for patients, family and carers. Brain cancer care coordinators may also be called: neuro-oncology care coordinator, brain cancer nurse navigator, neuro-oncology clinical nurse consultant, or many other variants.

Limited access across Australia

Despite a demonstrated need, access to BCCCs is grossly limited. There are only 29 BCCCs available nationwide, providing one for every 69 newly diagnosed patients annually, without including those who require ongoing care over years or decades.[27]

Just five of these BCCCs are specialised for paediatric brain tumours. Existing BCCCs carry high caseloads, yet a quarter of roles are not full-time. This reduces the number of full-time equivalent roles to just 20.6 BCCCs, and the level of support for patients even further.[27]

29 There are only 29 brain cancer care coordinators nationwide, working in just 20.6 full-time equivalent positions.[22]

Almost a third of roles are not focused exclusively on brain cancer, which leads to BCCCs supporting multiple cancer types, complicating their workload, and constraining their focus.[27] In a critical system failure, the funding for this role is being partially met outside of public or private hospital funding, with at least a quarter of BCCC roles fully or partially funded by non-profit organisations.[27] The concentration of BCCCs in major cities on the east coast creates further challenges for Australians with brain cancer living in regional and rural areas, particularly those who are unable to drive or travel due to their disease. Nine out of ten

BCCCs are based in major cities on the east coast, as shown in Figure 1. Western Australia and South Australia each have only one BCCC, with none available in Tasmania and the Northern Territory.

The 'postcode lottery' associated with access to BCCCs undermines equity in cancer outcomes for Australians, a key goal of the Australian Cancer Plan. Without access to BCCCs, people with brain cancer experience inequitable hardship throughout their brain cancer journey, simply by living in the 'wrong' area.

“

Out of [my patients that I care for across] three different tumour types, CNS [central nervous system] patients are the cohort that are contacting me the most with medical questions related to treatment. ”

Clinical Nurse Consultant for Lung, Melanoma and CNS, Victoria

9 out of 10 BCCCs are based in major cities on the east coast of Australia.^[27]

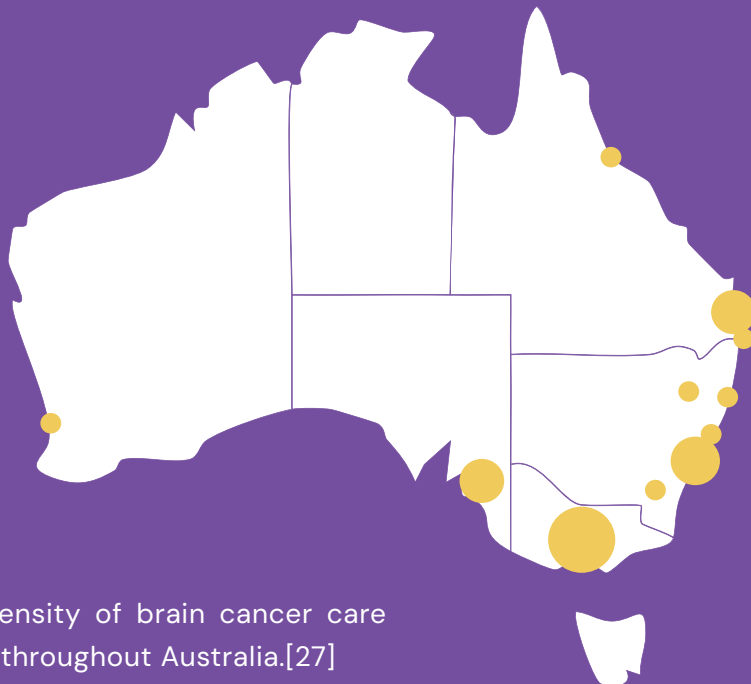


Figure 1 – Density of brain cancer care coordinators throughout Australia.^[27]

National approach to cancer care

Australia's national approach to cancer care is guided by the Australian Cancer Plan (ACP), a 10-year strategy aiming to improve cancer outcomes for all Australians.[28] Recognising

the importance of cancer care coordinators in achieving better outcomes, the plan identifies the Australian Cancer Nursing and Navigation Program (ACNNP) as a key implementation priority.[29]

About the Australian Cancer Nursing and Navigation Program (ACNNP)^[29]

Established in late 2023, the ACNNP aims to ensure all Australians with cancer can access high quality and culturally safe care. This program includes four components:

1. **The Cancer Navigation Service.** Led by Cancer Council Australia, this service connects people to multidisciplinary telehealth teams and provides referrals to clinically appropriate information and services.
2. **All-cancer nurse service.** Led by the McGrath Foundation, this service delivers 250 all-cancer nurses in health and hospital services across Australia.
3. **Child and Youth Cancer Hub.** Led by Canteen in collaboration with Camp Quality and Redkite, this service delivers navigation, support and counselling services for children and young people with cancer and their families.
4. **Specialist telehealth services.** Led by the non-government organisation sector, this service will provide specialist information, support and advice tailored to tumour type.

There is a critical omission in the ACNNP. The ACNNP does not recognise the highly complex and unique survivorship journey of brain cancer. This is a direct result of the lack of consultation with brain cancer advocacy groups and organisations, who were not invited to participate, prior to the finalisation of the ANCPP.

Since 2012, the brain cancer community has advocated for dedicated brain cancer care coordinators in budget submissions and correspondence with government ministers. BCCCs can have a significant impact on patient lives, thanks to the testimony of the many patients they speak to daily. Geoff's story on page 18 is one such example.

The benefit of BCCCs goes beyond the patient, carers and family. Improved access to support reduces inefficient utilisation in the already-strained Australian healthcare system,

creating capacity for additional care. All Australians stand to benefit from a government-led effort to address the shortage of BCCCs in Australia.

“

There is high level of urgency to have a dedicated [BCCC] as the diagnosis of brain cancer is devastating and debilitating in every aspect of their lives.”

AYA Clinical Nurse Consultant, Tasmania

Brain cancer care coordinators improve patient outcomes and experiences

The journey of an Australian with brain cancer is uniquely complex with numerous challenges due to the nature of brain cancer itself.

With over 100 types of brain tumours, varying symptoms, and prognosis dependent on age and cancer type, individuals face overwhelming uncertainty and a shifting landscape of medical needs.

BCCCs play a crucial role in navigating this challenging journey, improving both the quality of care and the quality of life for people living with brain cancer and their families or carers.

The benefits of BCCCs, as described by roundtable attendees, include:



Enhanced quality of life

With the support of a BCCC, individuals with brain cancer experience significant improvements in quality of life. BCCCs provide essential stability by guiding patients and parents of affected children through complex treatment options, coordinating care, and reducing the uncertainty surrounding this unpredictable disease.

Additionally, the support of BCCCs fosters mental wellness, by helping individuals feel more secure, informed, and focused throughout their treatment journey. This support extends into the

palliative and end of life periods, ensuring children, adolescents and adults with brain tumours receive the compassionate care and dignity they deserve.

For long-term survivors, such as those with low grade gliomas, BCCCs play a crucial role in managing symptoms that deteriorate over many years. This can include through enabling access to rehabilitation support, to improve function where possible. This continuous support enables survivors to maintain their quality of life for periods greater than 10 years, while managing significant impairments and high support needs.



A seamless, structured care journey

BCCCs offer a cohesive and structured approach from diagnosis to treatment, through palliative care and at end of

life. Brain cancer journeys are often fragmented as individuals move in and out of the health system. Over the disease continuum, Australians with

brain cancer will see clinicians across multiple specialities, access allied health, evaluate different treatment options, and receive varying levels of support. A lack of coordination in these stages leads to uncertainty, and delayed care, ultimately compromising patient outcomes. The coordination

effort of BCCCs ameliorates this, helping patients navigate the complexities of brain cancer while reducing the risk of getting lost in the healthcare system. By offering continuous, planned support, BCCCs ensure that each stage of care progresses seamlessly.



There is a growing need for specialised brain cancer care coordinators, given the complexity of their care needs. These roles are crucial in providing expert guidance, coordinating multidisciplinary care, and supporting patients and families throughout their treatment, ensuring improved outcomes and a more seamless healthcare experience.



Primary Brain Cancer Cancer Nurse Consultant (CNC), Queensland



Proactive and personalised health management

A key capability of BCCCs is ensuring individuals receive timely, personalised health management guidance. This guidance addresses symptom and medication management, as well as coordinated referrals to allied health and other supportive services. Because of the rapid progression of symptoms

and potential side effects that brain cancer patients experience, and frequent shifts in treatment, BCCC guidance is invaluable. By providing the right care at the right time, BCCCs help prevent complications, reduce hospitalisations, and ensure that patients receive the comprehensive support they need.



Community-centred support for better wellbeing

By coordinating care and addressing issues before they escalate, BCCCs minimise unnecessary time spent in emergency departments (EDs) and hospitals.[30] Roundtable attendees agreed that this enables individuals to remain in their communities, benefiting from the stability of familiar surroundings and healthier

environments. For people with brain cancer, this is vital, as a familiar environment helps reduce anxiety and stress. Maintaining routine and social connection with family and community supports emotional wellbeing, ultimately enhancing their quality of life.



Empowerment through resources and self-advocacy

By enhancing access to resources and essential information, BCCCs empower Australians with brain cancer and parents of children with brain tumours to advocate for their health. This may include guidance on which symptoms are 'normal' or concerning, information on accessible therapies to ease comorbidities, and referrals to health professionals with the right expertise for specific tumour types. This access is crucial for patients with brain cancer as they navigate complex medical information and rapidly changing symptoms, all while experiencing neurocognitive disability.

This expertise is particularly critical to support babies, young children and adolescents with brain tumours, who are unable to self-advocate and navigate the health system independently. Improved access to BCCCs supports parents or guardians in accessing care, specifically for paediatric brain tumours, which have symptoms, treatments, comorbidities and pathways distinct from adult-onset tumours. Parents are already concerned with making the best choice for their child's care, and having the right information to make informed choices and access age-appropriate community services significantly eases their burden.

Finally, BCCCs also support people with brain cancer in navigating complex systems to access a wide range of national, state and community resources, including the NDIS and My Aged Care. They provide practical assistance with applications, arrange reviews and assessments, and monitor the progress of applications. They also inform patients about services available through these support systems, helping them understand and secure relevant support. This expertise improves the timeliness of support received, which is particularly critical for patients facing short survival prognoses and rapid deterioration.



For [children] with high grade glioma and poor prognosis, access to services which help create happy memories with the family, improve emotional and mental wellbeing for all can be beneficial, especially for those left behind once the patient passes.

Senior Paediatric Oncology Nurse, Victoria

BCCCs empower people with brain cancer to take control of their care, enabling informed decision-making and active participation across their own brain cancer journey.

Brain cancer care coordinators support carers and family members

Brain cancer care coordinators can significantly enhance the experience and wellbeing of carers and family members. Roundtable attendees noted that when done, coordination of care will achieve:



Enhanced understanding and reduced anxiety

BCCCs are crucial in helping carers and families navigate the complex brain cancer landscape. By assisting caregivers to coordinate the individualised care needed for people with brain cancer, BCCCs help instil confidence in their ability to provide effective support to their loved one. This is particularly

important for parents managing intense anguish while trying to make the best decisions for their child with brain cancer. Guidance provided by BCCCs significantly reduces uncertainty and anxiety, alleviating feelings of overwhelm and minimising decision fatigue, which can lead to carer burnout.



I have witnessed how dedicated BCCCs can support parents and their children with brain cancer far better than general nurses on the ward, despite our best efforts to do so.



Senior Paediatric Oncology Nurse, Victoria



Proactive care planning and navigation support

BCCCs support carers and family members in proactively planning for the evolving care needs of brain cancer patients. The unpredictable nature of the disease can lead to urgent situations that require immediate attention, particularly as new symptoms arise. During a difficult and emotional journey, BCCCs

help identify the right time to initiate planning for palliative care, ensuring a more comfortable transition to end of life, with less stress for carers and family.

Critically, supporting family members and carers to navigate the NDIS and My Aged Care enables

them to access essential resources to meet the dynamic demands of this disabling cancer. This support gives carers confidence and reduces

their stress, allowing them to focus on providing compassionate care.



Being there to support patients and families during this unbelievably difficult time is such a valuable service to have to brain cancer sufferers in our area, whether it is for medical advice, treatment education, support services introduction, or even someone just to talk to.



Brain Cancer Care Coordinator, New South Wales



Empowerment through access to community resources

By leveraging their connections to community supports, BCCCs help carers identify and access specialised resources tailored to the unique challenges of brain cancer. Roundtable attendees identified the value of supportive resources, including information,

services, or peer support and learnings from others on the same journey. In providing access to these community resources, carers feel more empowered and secure while providing care, knowing they can draw upon their support network.



Maintaining normalcy and purpose

A vital role that BCCCs fulfill is helping carers and families maintain a sense of normalcy. With their support, carers and families can continue their daily routines, including work and personal commitments, which is essential for reducing stress, preventing burnout, and alleviating financial pressure.

When approaching end of life care, BCCCs ensure carers and families have access to emotional and practical support, easing the transition and helping them navigate feelings of grief and loss of purpose after the patient's passing. Ultimately, BCCCs support and assist carers and families with facing these inevitable challenges with more confidence and resilience.

BCCCs empower carers and families by reducing uncertainty, enhancing confidence, and ensuring access to essential resources, enabling them to navigate the complex brain cancer journey.

Better access to brain cancer care coordinators reduces health system strain

The integration of BCCCs into the Australian healthcare system offers significant economic advantages by enhancing patient, carer, and family outcomes. As these outcomes improve, roundtable attendees agreed that long-term benefits for the health system are evident:



Reducing healthcare system burden

Access to BCCCs alleviates the burden on the Australian healthcare system. A recent study found access to a BCCC resulted in a significant reduction in ED presentations and hospital admissions for people with brain cancer. Specifically, a 24 per cent decrease in

aggregate length of stay was associated with BCCC involvement.^[30] By enhancing continuity of care, BCCCs reduce the need for hospital-based interventions and support an overall reduction in healthcare resource demands.

24 per cent decrease in length of stay for patients with access to BCCC.^[30]



Proactive management and crisis prevention

Proactive management by BCCCs helps identify and address issues early, reducing the need for costly emergency interventions. By ensuring timely attention to challenges, symptom management, and medication adjustments, this support keeps patients out of hospital, avoiding gaps in care that could otherwise

lead to urgent, reactive treatments in already strained EDs. By preventing crisis situations and ensuring more continuous, proactive support, BCCCs reduce the frequency of high-cost ED visits and other urgent care expenses, easing the strain on healthcare resources.



Efficient utilisation of health services

The involvement of BCCCs improves health system efficiency by coordinating the most appropriate resources for each patient's specific needs and goals. Without BCCC guidance, people with brain cancer and families may use services less efficiently due to limited understanding of available options. This leads to unnecessary, duplicate or inappropriate use of health resources. For example, without

navigation support, a person with brain cancer may visit multiple specialists seeking appropriate care. BCCCs bridge this gap by coordinating care with the right clinicians, allied health and community resources, promoting preventive measures over reactive hospital interventions. This targeted resource management reduces the financial burden of unnecessary visits and alleviates healthcare system strain.

BCCCs reduce strain on the health system by providing coordinated, proactive care that prevents unnecessary hospital admissions and streamlines access to essential treatments.



How Anita helped Geoff navigate his journey

Leading into New Years 2018, Geoff had been busy working in his electrical business. He and his staff were looking forward to the Christmas Break. On New Years Eve Geoff started to have trouble finding words, and within four short days he was diagnosed with a suspected high grade brain tumour, likely a Glioblastoma.

The weeks flew by, as he was operated on by a neurosurgeon, monitored by a neurologist and eventually was introduced to a radiation oncologist. Then came six long gruelling weeks of combined daily radiation and chemotherapy. Over the ten weeks from diagnosis to recovery from treatment, he was routinely admitted to ED with a myriad of side effects and symptoms.

During one of his radiation sessions, a woman by the name of Anita introduced herself to us. She assured him that she was there to guide the processes within the hospital.

In the eight weeks since he was first admitted, he had moved through multiple hospital departments, including emergency and the ward, never having been given a point of contact for anyone.

The relationship with Anita formed over another 3.5 years. She was a CNS and AYA CNC, and for the entire period that he was in treatment or being monitored by Oncology, she remained by his side in regular contact.

There were times he awoke, unable to feel one of his arms. A call to Anita allowed him to run through his symptoms and for her to seek advice from the Oncologist. The response came by phone shortly after with advice on next steps, or a confirmation to amend medications.



On other occasions, particularly during a reduction of his steroid dose, she would call daily to check on symptoms and monitor the reduction rate.

His CNC was in constant contact with the specialist team, and could provide updates to MRI results. She would sit on the MDT meetings each Friday where cases were discussed, and could pass through information promptly if changes in his treatment regime were needed, or if an earlier appointment was necessary.

This oversight meant that Geoff only needed to attend routine clinic every three weeks. Admissions to ED were limited to seizures and extreme reactions to medications. The level of contact meant there was very little time between a problem arising and a solution being found. When an admission was deemed necessary, it could be discussed and his CNC would call ED to advise of his arrival and the need to fast-track him to the ward. Again, a level of understanding and compassion for the horrendous time that people would spend in ED was alleviated by open communication.

When Geoff entered the final phase of his disease, and was discharged from Oncology and into Palliative Care, the role of the CNC ceased. It was saddening, as the angst of the unknown returned swiftly, and the reminder of where it all began – nobody to ask questions of, little comprehension from the new team of his journey or how to communicate to his needs. Our personal touch, what made it somewhat comprehensible, had left us as her role was not funded for Palliative Care.

Geoff passed away in June 2022. His CNC came to visit him in his home, in his very last week of life, in her own time – to say goodbye.

Geoff's story is told by Fiona.



Next steps: the roadmap to better brain cancer care

The need for better brain cancer care in Australia is undeniable, and now is the time to act.

Across the nation, children, adolescents, and adults face poor survival rates that have remained largely unchanged for over 30 years, insufficient research funding, and significant challenges for patients, carers, and families. Australians and their families living with brain cancer need national coordination and urgent funding to enable equitable access and outcomes commensurate with other cancer types.

Attendees of the roundtable, including BCCCs, social workers, researchers, and patient advocates, all agreed a national approach to strengthening support for BCCCs is crucial to embedding better brain cancer care within the Australian health system. Together, they have outlined a clear roadmap for policymakers to improve outcomes for the brain cancer community:

1.

Establish a national working group

Form a diverse, multidisciplinary working group to lead the design, development, and strategic guidance of the BCCC program. Utilising the expertise of current BCCCs, medical professionals, allied health professionals, researchers and patient advocates, the group's primary objective is to ensure a balanced approach to equity, efficiency, and adaptability across all Australian states and territories. Representation of priority groups as outlined in the Australian Cancer Plan will be ensured, including Aboriginal and Torres Strait Islander people, children and young adults, LGBTQIA+ people, people living with disability and people living in rural and remote areas.

2.

Co-design a national Model of Care

Through the working group, co-design a model of care that can achieve equity and consistency across Australia while remaining flexible for local needs adaptation and effective integration within the broader health system. Building on current efforts made by the brain cancer community, this model should evolve by incorporating:

- **Tumour- and age-appropriate pathways:** Develop distinct pathways tailored to the unique needs of children, AYA, and adults with brain cancer. Additionally, create pathways that reflect the specific requirements of various brain tumour types, such as high grade and low grade gliomas, to ensure appropriate care.
- **ACNNP integration:** Ensure alignment with the Australian Cancer Nurse Navigator program to support cohesion with national policy efforts.

- **Public, private and care integration:** Develop mechanisms that ensure coordinated care across the public, private and community sectors, making the model adaptable to patients' healthcare settings.
- **Regional access equity:** Ensure consistent access to BCCC services across rural, remote and metropolitan areas, reducing geographic disparities in access.
- **Data collection and sharing:** Integrate tools for data capture, sharing, and analysis via existing cancer registries and online health portals to monitor patient outcomes, inform decision-making, and support continuous improvement.
- **Psychosocial and peer support for BCCCs:** Establish a structured peer support network and access to psychosocial resources to address the emotional toll on BCCCs themselves. This may include a mentorship program where experienced BCCCs can guide and support those new to the role.
- **Education and training:** Develop training pathways in brain cancer navigation, symptom management, and multidisciplinary coordination to equip BCCCs with the skills needed for their complex roles.

3.

Site mapping and capacity assessment

Conduct a thorough assessment of healthcare sites across Australia to identify those with the infrastructure, workforce, and capacity to implement the BCCC model of care effectively. This assessment should include:

- **Integration potential:** Evaluate each site for its ability to incorporate the BCCC model within existing healthcare models and patient pathways.
- **Outreach capability:** Identify sites that can extend services to regional and remote communities, facilitating better access to BCCC support in these areas.
- **Access to specialised services:** Prioritise facilities offering essential services such as neuro-oncology and psychosocial support to facilitate a multidisciplinary approach to brain cancer care.
- **Flexibility in service delivery:** Assess each site's capacity to tailor the BCCC model to local needs, addressing placed-based community challenges and resources.

4.

Define and standardise workforce competencies

Establish clear guidelines for the qualifications, skills, and career pathways of BCCCs, creating a foundation for a sustainable and capable workforce. Adapting core processes and standards of the ACNNP, key elements will include:

- **Core competencies and expertise:** Define the foundational skills, knowledge, and experience required of BCCCs. This should encompass strong clinical knowledge, effective relationship-building skills, psychological support capabilities, and adept coordination of multidisciplinary care.
- **Early involvement and continuity of care:** Standardise protocols for the early integration of BCCCs into the patient journey, ideally at diagnosis or as early as possible thereafter, to establish continuity of care, build trust, and optimise long-term outcomes.
- **Clear career pathways:** Define pathways that clearly outline career progression for BCCCs, strengthening recruitment and retention while building professional development opportunities across regions.

5.

Develop a governance and implementation plan

Create a governance structure that ensures accountability, quality, and consistency across the BCCC program, with oversight from a central organisation:

- **Program governance and standards:** Designate an appropriate organisation to oversee program standards and quality assurance.
- **Sustainable funding and administration:** Identify funding streams and resources to support the long-term administration and scaling of the program, engaging at both federal and state levels to secure investment for BCCCs.
- **Monitoring and evaluation:** Develop evaluation metrics to continuously monitor program effectiveness, patient outcomes, and system efficiencies, enabling data-driven adjustments to the program over time and evidence of value. Draw upon metrics developed for the ACNNP to enable cohesive evaluation across the Australian cancer care sector.

Combining these steps will create a robust, patient-centred BCCC program that improves access to quality care, reduces inequitable disparities across states and regions, and supports a sustainable workforce equipped to navigate the complexities of brain cancer care.

People with brain cancer face extraordinary challenges and deserve compassionate, tailored care that meets their unique needs. Reshaping the landscape of brain cancer support is essential to ensure that no one embarks on this complex journey alone.

The need for better brain cancer care in Australia is undeniable, and now is the time to act.

Abbreviations

Abbreviations	Description
ACP	Australian Cancer Plan
ACNNP	Australian Cancer Nursing and Navigation Program
ABTC	Australian Brain Tumour Collaborative
AYA	Adolescent and Young Adult
BCCC	Brain Cancer Care Coordinator
CNC	Cancer Nurse Consultant
CNS	Central Nervous System
ED	Emergency Department
LGBTQIA+	Lesbian, Gay, Bisexual, Transgender, Intersex, Queer and Asexual people
NDIS	National Disability Insurance Scheme

References

1. Department of Health and Aged Care. Australian Brain Cancer Mission: Department of Health and Aged Care; 2024. Available from: <https://www.health.gov.au/our-work/mrff-australian-brain-cancer-mission>.
2. University of Newcastle. Mark Hughes Foundation Centre for Brain Cancer Research; 2024. Available from: <https://www.newcastle.edu.au/research/centre/mhf-brain-cancer-research>.
3. Cancer Australia. Brain cancer: Cancer Australia; 2024 Available from: <https://www.canceraustralia.gov.au/cancer-types/brain-cancer/statistics>.
4. Cancer Australia. 5-year relative survival from diagnosis: National Cancer Control Indicators; 2022. Available from: <https://ncci.canceraustralia.gov.au/outcomes/relative-survival-rate/5-year-relative-survival-diagnosis>.
5. Australian Institute of Health and Welfare. Brain and other central nervous system cancers: Australian Institute of Health and Welfare; 2017. Available from: <https://www.aihw.gov.au/getmedia/d2914a17-052e-45bb-bbd3-17047c7d5da1/20566.pdf?v=20230605165404&inline=true>.
6. Australian Institute of Health and Welfare. Cancer data in Australia: Australian Institute of Health and Welfare; 2024. Available from: <https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/overview>.
7. Australian Institute of Health and Welfare. Australia's children: Australian Institute of Health and Welfare; 2022. Available from: <https://www.aihw.gov.au/reports/children-youth/australias-children/contents/health/cancer-incidence-survival>.
8. Children's Cancer Institute. Brain cancer: Children's Cancer Institute; 2024. Available from: <https://www.ccia.org.au/about-the-institute>.
9. Valvi S, Manoharan N, Mateos MK, Hassall TE, Ziegler DS, McCowage GB, et al. Management of patients with diffuse intrinsic pontine glioma in Australia and New Zealand: Australian and New Zealand Children's Haematology/Oncology Group position statement. *Med J Aust*. 2024;220(10):533-8.
10. Grisold W, Grisold S, Guekht A, Ruda R. Managing Challenging Behaviour in Brain Tumour (BT) Patients. In: Bartolo M, Soffiatti R, Klein M, editors. *Neurorehabilitation in Neuro-Oncology*. Cham: Springer International Publishing; 2019. p. 151-66.
11. Pendergrass JC, Targum SD, Harrison JE. Cognitive Impairment Associated with Cancer: A Brief Review. *Innov Clin Neurosci*. 2018;15(1-2):36-44.

12. Young JS, Al-Adli N, Sibih YE, Scotford KL, Casey M, James S, et al. Recognizing the psychological impact of a glioma diagnosis on mental and behavioral health: a systematic review of what neurosurgeons need to know. *Journal of Neurosurgery*. 2023;139(1):11–9.
13. Paterson C, Roberts C, Li J, Chapman M, Strickland K, Johnston N, et al. What are the experiences of supportive care in people affected by brain cancer and their informal caregivers: A qualitative systematic review. *J Cancer Surviv*. 2024;18(5):1608–29.
14. Sterckx W, Coolbrandt A, Dierckx de Casterlé B, Van den Heede K, Decruyenaere M, Borgenon S, et al. The impact of a high-grade glioma on everyday life: A systematic review from the patient’s and caregiver’s perspective. *European Journal of Oncology Nursing*. 2013;17(1):107–17.
15. Cancer Council NSW. Living with a brain or spinal cord tumour: Driving: Cancer Council NSW; 2024. Available from: <https://www.cancercouncil.com.au/brain-cancer/living-with-a-brain-tumour/driving/>.
16. Frances SM, Velikova G, Klein M, Short SC, Murray L, Wright JM, et al. Long-term impact of adult WHO grade II or III gliomas on health-related quality of life: A systematic review. *Neurooncol Pract*. 2022;9(1):3–17.
17. Kumthekar P, Raizer J, Singh S. Low-Grade Glioma. In: Schramm J, editor. *Advances and Technical Standards in Neurosurgery*. 35: Springer Vienna; 2014.
18. Aiman W, Gasalberti D, Rayi A. Low-Grade Gliomas. *StatPearls* [Internet]. Treasure Island (FL): StatsPearls Publishing; 2023.
19. Klein M, Heimans JJ, Aaronson NK, van der Ploeg HM, Grit J, Muller M, et al. Effect of radiotherapy and other treatment-related factors on mid-term to long-term cognitive sequelae in low-grade gliomas: a comparative study. *Lancet*. 2002;360(9343):1361–8.
20. Bruce M, Gumley D, Isham L, Fearon P, Phipps K. Post-traumatic stress symptoms in childhood brain tumour survivors and their parents. *Child Care Health Dev*. 2011;37(2):244–51.
21. National Advocacy Service. NDIS Plan Statistics. In: Wilson M, editor.: National Advocacy Service; 2024.
22. NDIS. National Dashboard as at 30 June 2024: NDIS; 2024. Available from: <https://www.ndis.gov.au/media/7203/download?attachment>.
23. Ownsworth T, Goadby E, Chambers SK. Support after brain tumor means different things: family caregivers’ experiences of support and relationship changes. *Front Oncol*. 2015;5:33.
24. Whisenant MS, Crane S, Stewart M, Milbury K. The Bereavement Experience for Partners of Patients With Central Nervous System Tumors. *Oncol Nurs Forum*. 2022;49(2):151–7.

25. Willis KD, Reid MP, Fox A, Kleva CS, Sherwood P, Loughan AR. The impact of a primary brain tumor diagnosis on caregivers: Insights from the patients' perspective. *Supportive Care in Cancer*. 2024;32(9):595.
26. PoCoG. About The Brains Program: The Psycho-oncology Co-operative Research Group (PoCoG); 2024. Available from: <https://www.pocog.org.au/the-brains-program>.
27. National Advocacy Service. Survey of Brain Cancer Care Coordinators in Australia, October 2024. In: Service NA, editor. 2024.
28. Cancer Australia. Australian Cancer Plan: Cancer Australia; 2024. Available from: <https://www.australiancancerplan.gov.au/welcome>.
29. Department of Health and Aged Care. Australian Cancer Nursing and Navigation Program: Department of Health and Aged Care; 2023. Available from: <https://www.health.gov.au/our-work/australian-cancer-nursing-and-navigation-program#about-the-program>.
30. Hong M, Leigh L, Ballinger C, Reeves P, Gooley A, Nixon S, et al. The impact of brain cancer care coordinators on healthcare utilization and outcomes in patients with glioblastoma. *Neuro-Oncology Practice*. 2024;11(5):575-82.




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