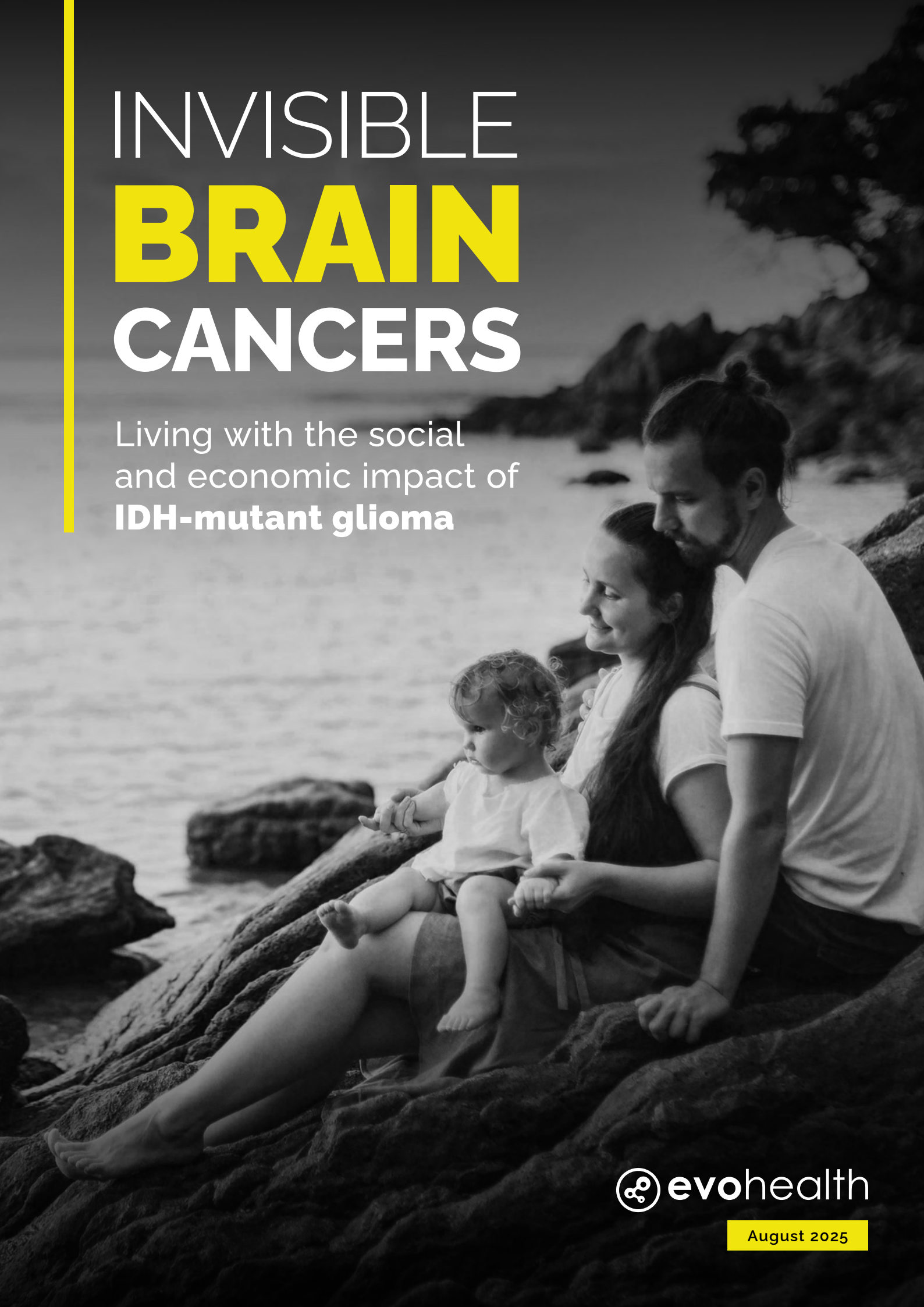
INVISIBLE BRAIN CANCERS

Living with the social and economic impact of **IDH-mutant glioma**



evohealth

August 2025

Evohealth acknowledges that we work on the traditional lands of many Aboriginal clans, tribes, and nations.

We commit to working in collaboration with Aboriginal and Torres Strait Islander communities and peoples to improve health, emotional and social well-being outcomes in the spirit of partnership.

About **Evohealth**

The delivery of healthcare is complex.
Our focus is not.

Better health for all.

INVISIBLE BRAIN CANCERS

LIVING WITH THE SOCIAL AND ECONOMIC IMPACT OF IDH-MUTANT GLIOMA

CONTENT.

ABOUT **THIS REPORT**

Background

Invisible brain cancers: living with the social and economic impact of IDH-mutant glioma is an evidence-based report describing the profound difficulties of living with and managing isocitrate dehydrogenase (IDH) mutant glioma in Australia. The report outlines five key recommendations to improve the lives of people with IDH-mutant glioma, their carers, and families.

Approach

The report was independently prepared by Evohealth, a specialist health advisory firm, in partnership with an expert Advisory Committee. It was informed by a comprehensive review of published academic and grey literature, interviews with Australian clinicians, researchers and patient advocacy groups, and a cohort-based economic model.

Servier Australia provided funding for this report, but did not participate in its development to ensure Evohealth's independence.

ACKNOWLEDGEMENTS

Evohealth wishes to acknowledge the ongoing support from the individuals and organisations who contributed to this project, particularly those who shared their stories and experiences with IDH-mutant glioma.

We thank the Advisory Committee, whose keen and perceptive input was critical to the development of this report. The committee comprised the following members:

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PoCoG Psycho-oncology Co-operative Research Group

peace of mind foundation

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The Brain Cancer Group

Cure Brain Cancer Foundation

University of Newcastle Australia

Mark Hughes Foundation Centre for Brain Cancer Research

ABCARA Australian Brain Cancer Research Alliance

ABCF Australian Brain Cancer Foundation

Children's Cancer Institute

Clinical Oncology Society of Australia

ANZSNP The Australian & New Zealand Society for Neuropathology

Brain Cancer Australia

rare cancers Australia

ANZCHOG Australian & New Zealand Children's Haematology/Oncology Group

NRF

EXECUTIVE **SUMMARY**

For far too long, the impacts of isocitrate dehydrogenase (IDH)-mutant glioma, a rare and incurable brain cancer, have been overshadowed by better-known brain cancers like glioblastoma (GBM). Yet, in 2024 over 3,000 Australians and their families lived with the effects of IDH-mutant glioma. [1] In fact, it is the most common malignant primary brain tumour diagnosed in adults under 50 years of age. [1, 2]

While GBM strikes with terrifying speed, IDH-mutant glioma slowly erodes health and independence over many years. This disease causes permanent brain injury and forces young, productive Australians into a relentless cycle of decline, treatment and uncertainty, steadily diminishing their quality of life and ultimately leading to premature death. Yet, this disease and the complex survivorship needs of those afflicted remain invisible to policymakers, the health system, research funders and society.

IDH-mutant glioma is a chronic and relentless cancer that disrupts the lives of young Australians, imposing profound physical, emotional, and financial burdens. Despite its devastating impact, progress in diagnosis and treatment remains stagnant, psychosocial support is inadequate, and systemic gaps leave many patients and carers without guidance and comprehensive support. This report examines these critical challenges and highlights the urgent need for action.

> *"This is a young group of people who, at the peak of their lives, and in their most productive years, are diagnosed with an incurable cancer. The impact on them is severe, devastating, and it's not recognised at all."*
>
> **- Professor Hui Gan, Medical Oncologist**

A chronic incurable brain cancer

With diagnosis typically occurring between 20 and 45 years of age, IDH-mutant glioma hits people in their prime, as they build careers, raise families, and contribute to society. [3] Unlike many cancers, its chronic and incurable nature means this disease is endured for five to 13 years, depending on tumour type and grade, with some people living with it for over 20 years. [1, 4, 5]

During this time, patients face multiple rounds of brain surgery, chemotherapy, and radiation therapy to control tumour growth. [6] While these treatments delay cancer progression, they do not offer a cure. They are also likely to harm healthy tissue, causing permanent brain injury that exacerbates cognitive decline, physical disabilities, and psychological distress. The resulting cognitive dysfunction is comparable to a traumatic brain injury, disrupting decision-making, focus and memory. [3, 5]

The size and location of an IDH-mutant glioma dictates not only the symptoms patients experience, ranging from headaches and seizures to speech impairments, emotional dysregulation, and physical disability, but also their prognosis. For example, tumours located in areas of the brain that control essential functions, such as the motor function or language centres, are associated with severe functional impairments and poorer outcomes. [7]

The progression of these slow growing brain cancers is unpredictable, further complicating survivorship. Tumour growth and recurrence are difficult to anticipate, leaving patients trapped in cycles of active treatment and watch-and-wait periods, where 'scanxiety' becomes a constant shadow. [3] Seizures, a common symptom, often render people unable to drive, diminishing their ability to work or care for their families, and can lead to further disabilities. Cognitive and behavioural changes strain relationships and communication, further isolating patients and their families. [8]

> *I am very isolated in my daily life and only able to socialise with my immediate family. I don't have a partner as my ability to leave the house to meet someone is greatly limited, and I can't hear well in public spaces. My inability to work further isolates and restricts me, and I've had to survive on the disability pension for all my adult life.*
>
> **- Helen, aged 33, Victoria, diagnosed with Oligodendroglioma in 2017**

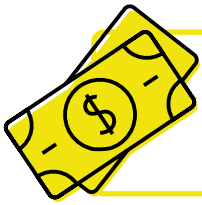
The impact of IDH-mutant glioma extends far beyond the patient. Informal carers shoulder a burden of 1.8 million hours of unpaid care annually while grappling with the emotional toll of supporting loved ones through behavioural changes, loss of independence, and continual decline. [1, 9] Over years or even decades, children will endure watching their parent's decline as they battle a slow, progressive, and debilitating cancer. This prolonged exposure to their parent's physical decline, encroaching cognitive disability and psychological distress leaves children with lasting trauma, shaping their lives for years to come.

> *The impact of this invisible disease does not end with the patient. It crosses generations and will affect families for decades to come.*
>
> **- Professor Haryana Dhillon, Behavioural Scientist**

Unbearable cost burden

There are also far-reaching impacts on society. In 2024 alone, IDH-mutant glioma robbed Australians of 9,125 years of life, averaging 22 years lost per patient due to premature death, and 3,715 years of healthy life due to disability. [1] When combined, this total of 12,840 disability-adjusted life years (DALYs) lost, is staggering, disproportionately affecting young adults. Evohealth's modelling estimates the total societal cost of IDH-mutant glioma at $3.5 billion annually, a figure set to rise to $4.7 billion by 2050 if action is not taken. Supporting a single person with IDH-mutant glioma costs approximately $1.1 million per year, reflecting the immense societal strain caused by a cancer frequently overlooked. [1]

$3.5 billion annual IDH-mutant glioma burden in Australia. [1]



~$1.1 million each year to support one person with IDH-mutant glioma. [1]

9,125 years total or **22 years per patient** of life lost due to premature death from IDH-mutant glioma in 2024. [1]

3,715 years of healthy life lost due to disability from IDH-mutant glioma in 2024. [1]

A significant portion of this economic burden comes from lost productivity. Patients often lose the ability to work full-time, or at all, due to debilitating symptoms, treatment side effects, and cognitive decline, leading to an estimated $74.8 million in productivity losses annually. [1] This burden extends to carers, often close family members, who reduce their working hours or leave employment entirely to provide care, resulting in an additional $71.6 million each year. [1] Combined, the total productivity loss for patients and carers reaches $146.4 million annually, highlighting the hidden but substantial economic cost of this slow-progressing cancer.

~$74.8 million per year **productivity loss** for **people** with IDH-mutant glioma. [1]

~$71.6 million per year **productivity loss** for **carers** supporting a person with IDH-mutant glioma. [1]

~$53,460 financial burden per household each year. [1]

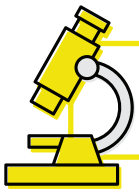
We must do better for Australians living with glioma

Australians living with IDH-mutant glioma endure relentless disease progression and taxing treatments for years, potentially a decade or more. Progress in treatments has stagnated, and there is no cure in sight.

To improve survivorship, Australians living with this insidious and brain-damaging disease need more effective treatment options, research funding, clinical trials and a coordinated, integrated clinical care pathway. Only two clinical trials for this cancer are underway in Australia at present, and just three research projects specifically investigating IDH-mutant glioma have been funded since 2018. [10-13] Of the $126 million allocated to the Australian Brain Cancer Mission, a mere 0.47 per cent has been directed toward IDH-mutant glioma. [10, 14] This inequity in research and trial funding must be addressed, if we are to provide hope for people living with this brain cancer in Australia.

We also need to better articulate the optimal care pathway for IDH-mutant glioma patients. This should include coordinated access to psychosocial support, rehabilitative care and treatment across their complex survivorship journey, which can span many years.

Australia is poorly equipped to support the ongoing needs of patients with this cancer, leaving them and their families to navigate a fragmented system with little guidance. Patients often feel isolated, with cognitive impairments and a lack of documented care pathways making it difficult to access essential services and manage evolving challenges. [15] Articulating this care pathway, including supportive care needs, is vital to equipping patients, their carers and families with the information they need.



Of **$126+ million** available in the Australian Brain Cancer Mission, IDH-mutant glioma specific projects have received **0.47 per cent of funding.** [10, 14]

A critical part of the solution are Brain Cancer Care Coordinators (BCCCs), who can help patients navigate care requirements, advocate for their needs, and assist with obtaining services, such as National Disability Insurance Scheme (NDIS) funding. [16] Despite well-established benefits, including a documented 24 per cent reduction in length of hospital stays, there are only 29 BCCCs nationwide and most are concentrated in urban centres. [15] Urgent investment is needed to expand these roles, ensuring all IDH-mutant glioma patients and carers in both metropolitan and rural/remote areas receive the support they deserve.

Within this coordinated care pathway, it is critical to recognise the substantial psychosocial impact of living with a chronic brain cancer. Integrated support remains absent. [17] Patients and carers face significant distress, with untreated depression reducing survival from 10–12 years to 3–6 years. [18, 19] Despite this, baseline psychosocial assessments and monitoring are absent from ongoing care, leaving critical needs undetected and unaddressed. [18, 20] There are significant barriers to psychosocial care, including long waiting lists for public services, prohibitive costs for private care and limited availability of services in rural and remote areas. [21, 22] Programs such as that provided by the Telehealth Making Sense of Brain Tumour Program (Tele-MAST), have demonstrated the clinical and economic benefit of addressing this need, reducing anxiety and depression while saving $4,327 per patient annually. [18, 20]

$4,327 saved per patient with telehealth-delivered psychosocial support compared to standard care. [18, 20]

A critical foundation of psychosocial support is rehabilitative care, which can be as effective for restoring brain function in brain cancer patients as it is for stroke. [21] Yet, despite its role in maximising function, improving quality of life and minimising long-term care needs, it is not routinely integrated within referral pathways. Addressing the psychosocial and rehabilitative care needs for those living with this chronic cancer is critical to managing the long-term impacts of this disease, as well as for reducing the burden on caregivers and families.

Finally, we need to recognise that caring for someone with IDH-mutant glioma will only grow more complex, and overwhelming, as the disease progresses. In 2024, carers provided 1.8 million hours of unpaid care, yet their contributions remain poorly recognised. [1] They face significant challenges, from managing treatments and household responsibilities to supporting patients through behavioural and cognitive changes. Many experience fatigue, anxiety, and financial strain, contributing to $71.6 million in national productivity losses. [1] This must be recognised and better supported, including through streamlined access to income support mechanisms.

Making the invisible, visible

Every year, IDH-mutant glioma robs 3,230 Australians of their health, independence, and future. People living with this chronic cancer do so in silence, with a disease that is largely invisible to, and outside the reach of, current government policy and action.

Our expert Advisory Committee have devised five recommendations that, if actioned, can transform the experience of people living with IDH-mutant glioma from one of invisibility to one of empowerment and support.

RECOMMENDATION 1

Acknowledge and invest in the long-term treatment, support and research funding needs of IDH-mutant glioma as a chronic cancer within the Australian Brain Cancer Mission.

RECOMMENDATION 2

Recognise IDH-mutant glioma in the NDIS and Department of Social Services (DSS) criteria as a condition causing permanent disability to streamline access to financial support for patients living with IDH-mutant glioma, their carers and families.

RECOMMENDATION 3

Develop and fund a national BCCC model.

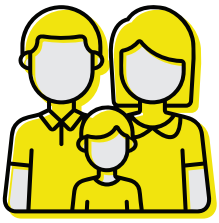
RECOMMENDATION 4

Develop a consensus statement to define the patient pathway, including treatments, monitoring, supportive care and workforce requirements needed to provide optimal care for Australians living with IDH-mutant glioma.

RECOMMENDATION 5

Develop a clinician-led submission to the Medical Services Advisory Committee for Medicare Benefits Schedule (MBS) funding to improve access to rehabilitative and psychosocial care for chronic brain cancers.

Australia needs to take action to address the immense challenges faced by those living with IDH-mutant glioma. For too long, patients and their loved ones have endured this devastating disease in isolation – unseen and unsupported. By implementing the solutions outlined in this report, we can transform their experience, ensuring they receive the care, resources, and recognition they deserve. It is time to prioritise these Australians and provide the support they need to face this journey with hope for a better future.



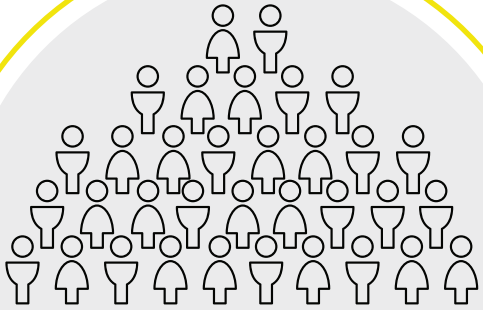
3,715 years of healthy life lost due to disability from IDH-mutant glioma in 2024. [1]

9,125 years total or **22 years per patient** of life lost due to premature death from IDH-mutant glioma in 2024. [1]

Survival can be between **five and 13 years**, depending on tumour type and grade, with some living for over 20 years. [1, 4, 5]

~$1.1 million each year to support one person with IDH-mutant glioma. [1]

1,814,124 hours of unpaid care provided by informal carers in 2024. [1]



3,230 Australians are living with IDH-mutant glioma in 2024. [1]

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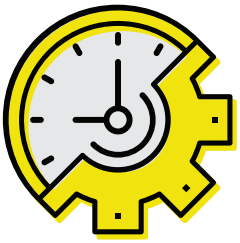

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Only two clinical trials currently available in Australia investigating treatment options for IDH-mutant glioma. [12, 13]

Only three IDH-mutant glioma research projects have received government funding since 2018. [10, 11]

Of **$126+ million** available in the Australian Brain Cancer Mission, IDH-mutant glioma specific projects have received **0.47 per cent of funding.** [10, 14]

$4,327 saved per patient with telehealth-delivered psychosocial support compared to standard care. [18, 20]

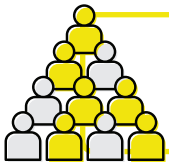
Rehabilitative care can be as effective in restoring function for brain tumour patients as it is for those recovering from stroke. [21]

A CHRONIC INCURABLE BRAIN CANCER

Isocitrate dehydrogenase (IDH)-mutant glioma is a relentless and chronic cancer that disrupts the lives of young Australians in their most productive years, reshaping their futures with significant uncertainty. This slow-moving yet unpredictable disease imposes profound physical, emotional, and financial burdens on patients and their loved ones. These challenges are exacerbated by stagnant progress in diagnosis and treatment, inadequate psychosocial support, and systemic gaps in our healthcare system, leaving many to navigate this journey alone. This report will examine these pressing issues, highlighting the urgent need for change.

In 2024, 3,230 Australians were living with IDH-mutant glioma. It is the most common malignant primary brain tumour diagnosed in adults under 50 years of age, [1, 2] accounting for approximately 20 per cent of all primary brain tumours. [4] For these adults, diagnosis typically occurs between the ages of 20 and 45, prime years for establishing a career and family. [3]

IDH-mutant gliomas affect both children and adults. While devastating for all, this report focuses on the adult population living with this disease.



3,230 Australians are living with IDH-mutant glioma in 2024. [1]

Survival **can be between five and 13 years**, depending on tumour type and grade, **with some living for over 20 years.** [1, 4, 5]

This brain cancer is incurable, recurrence is inevitable, and current treatments only delay progression and death. Survival time varies by tumour type and grade, with some surviving for five to 13 years, and others living more than 20 years. This variation is depicted in Figure 1. [1, 4, 5]

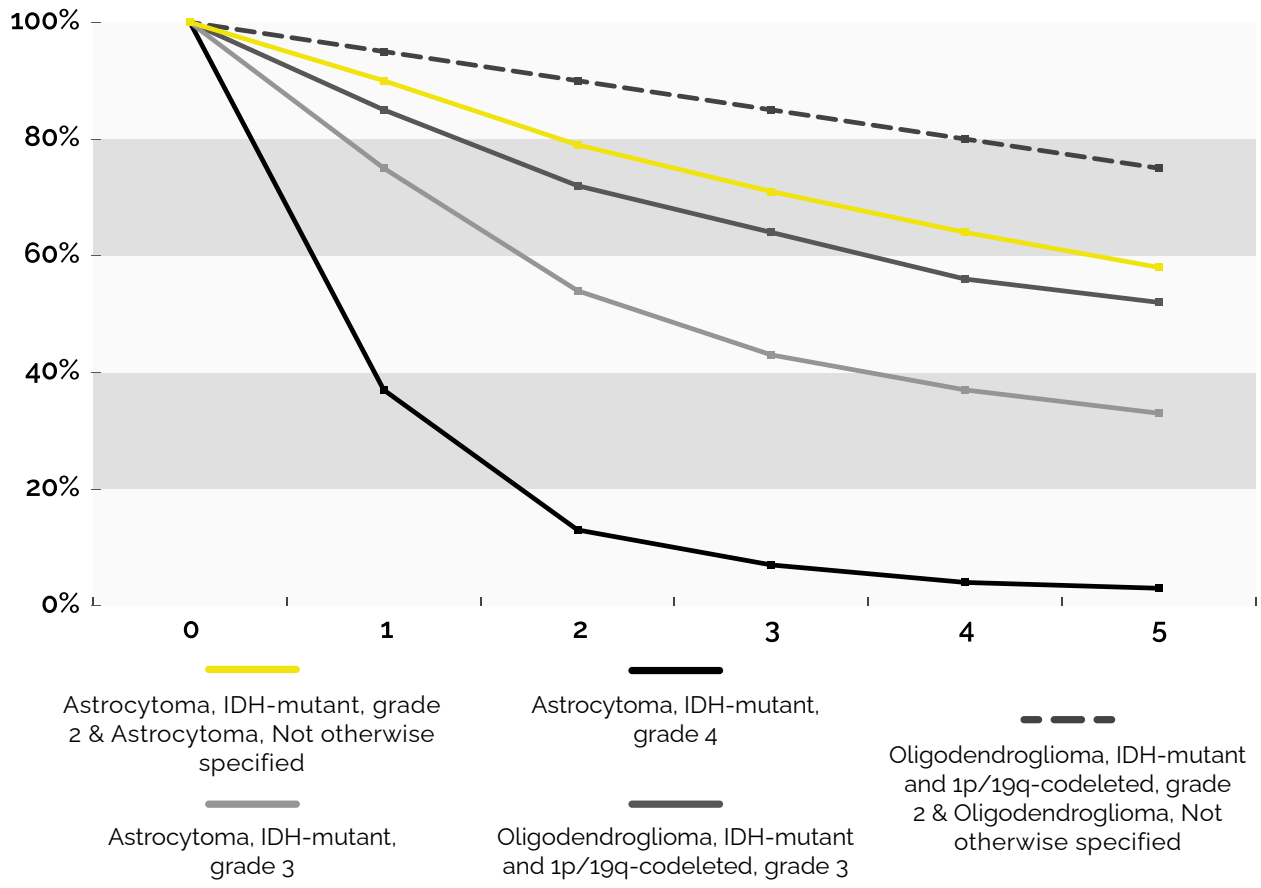


Figure 1: Five-year survival curve by tumour type

Source: Evohealth economic model [1]

The human toll of this incurable disease is immense. In 2024 alone, IDH-mutant glioma resulted in 9,125 years of life lost due to premature death, averaging 22 years per patient. An additional 3,175 years of healthy life were lost to disability, bringing the total burden to 12,300 disability-adjusted life years (DALYs). [1] These figures reflect the erosion of human potential and societal contribution caused by this disease, disproportionately affecting young, productive individuals.

9,125 years of life lost due to premature death from IDH-mutant glioma in 2024, averaging 22 years per patient. [1]

3,715 years of healthy life lost due to disability from IDH-mutant glioma in 2024. [1]

The economic burden of this invisible cancer is also significant and set to grow. Evohealth modelling estimates a total societal cost of $3.5 billion in 2024, projected to rise to $4.7 billion in 2050 if nothing changes. [1] These figures include treatment expenses, productivity losses and supportive care costs, which have a ripple effect on healthcare systems and individual households. These costs point to an urgent need for streamlined care pathways, increased investment in research, and innovative treatments to mitigate the rising costs.

Total societal cost of IDH-mutant glioma estimated to be **$3.5 billion** in 2024. [1]

Treatment alone accounts for a significant share of this burden, estimated at $118.7 million in 2024, or $37,734 per person. [1] Multiple General Practitioner (GP) consultations, emergency room attendances, and delays in obtaining testing delay diagnosis, further escalating cost. The nature of the disease necessitates frequent treatment cycles and ongoing magnetic resonance imaging (MRI) monitoring to detect malignant transformation, compounding the financial strain on Commonwealth, State, and Territory governments.

Ongoing IDH-mutant glioma treatment costs Commonwealth, State and Territory governments an estimated **$118.7 million** in 2024. [1]

Australians diagnosed with IDH-mutant glioma and their loved ones will bear the burden for many years. They will endure disabling symptoms, debilitating treatments, and constant monitoring while attempting to continue for as long as possible with regular life – work, friends, family and caregiving responsibilities. For many, this chronic, incurable brain cancer remains unseen by broader society.

For those diagnosed, every part of life will be affected; independence, livelihood, relationships, and even their sense of self. This devastating diagnosis reshapes the lives of young Australians in their prime - their dreams, family life, and future.

WHAT IS **IDH-MUTANT GLIOMA?**

Gliomas are central nervous system (CNS) tumours arising from abnormal growth in glial cells, the supportive cells of the brain and spinal cord. Unlike neurons, which send and receive messages, glial cells act like helpers, providing structure, protection, and nutrients to keep the brain functioning properly. [4] Two key types of glial cells involved in gliomas are astrocytes and oligodendrocytes, illustrated in Figure 2.

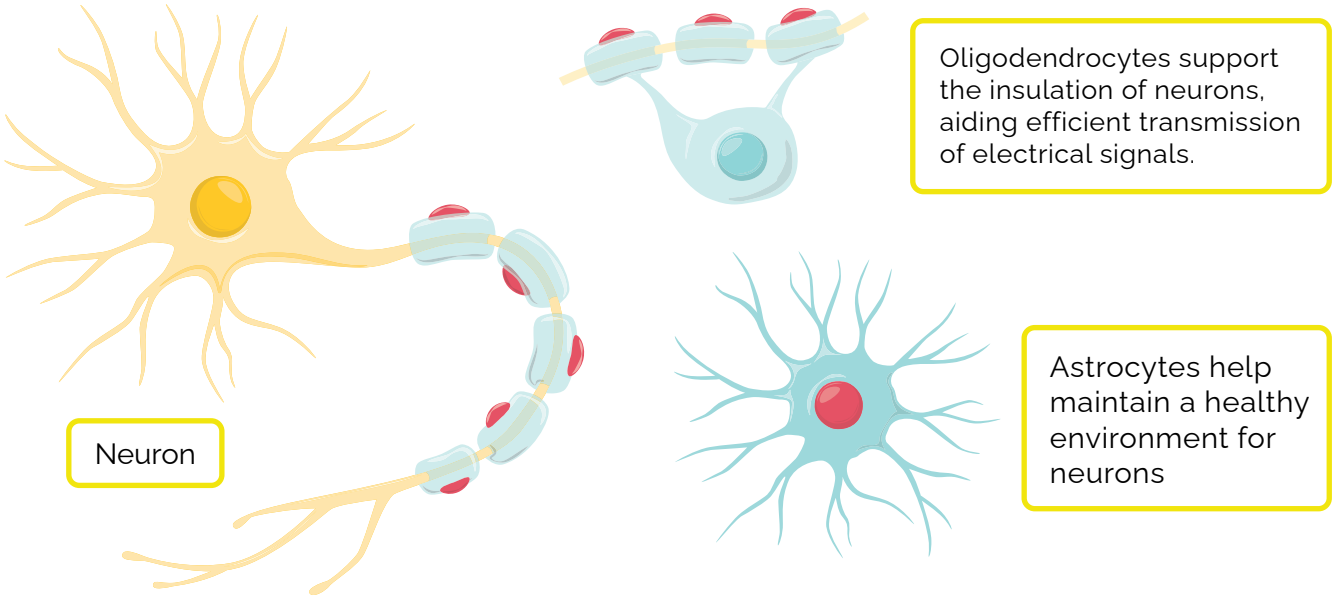


Figure 2: Appearance and function of astrocytes and oligodendrocytes *Source: Evohealth [23, 24]*

Several types of gliomas exist, each with varying symptoms, these prognoses and life expectancies. Traditionally, these gliomas were commonly referred to as low-grade (grade 2) or high-grade (either grade 3 or 4 tumours, based on their histological appearance (how tissues look under a microscope). [25] This method had limited utility as patient outcomes, such as survival times for high-grade tumours, were inconsistent. The discovery of genetic mutations in the IDH gene and other molecular markers has led to a more robust system for diagnosing and predicting outcomes and treatment responses. [25] Consequently, the categorisation of these tumours was refined in the most recent update to the World Health Organisation's Classification of Tumors of the CNS. [26]

According to this classification, adult-type diffuse gliomas with a mutation in the IDH gene are now referred to as IDH-mutant diffuse gliomas. These gliomas are further defined based on the presence or absence of two sections of DNA known as 1p and 19q. If an IDH-mutant tumour has 1p19q intact, it is an astrocytoma (grade 2-4), while if 1p19q is co-deleted, the tumour is an oligodendroglioma (grade 2-3). This report refers to these two IDH-mutant gliomas. [2]

If an adult-type diffuse glioma does not have an IDH mutation, and either looks high-grade or has a certain molecular profile, it is referred to as IDH-wildtype, glioblastoma (GBM) (grade 4).

Fast-growing gliomas like GBM are well researched and widely feared for their devastating impact, rapidly stripping patients of speech, movement and independence leading to death within months of diagnosis. [27]

In contrast, IDH-mutant gliomas receive less attention. Though slower growing, they primarily affect young adults, leading to life-altering progressive disabilities and premature death. Yet, societal awareness and understanding remain limited.

Children experience their own unique challenges with brain cancer

Paediatric brain cancers differ from adults in many ways including their classification, prognosis and treatment options. These cancers are referred to as paediatric low-grade glioma (pLGG) and not all involve IDH mutations.

Paediatric brain cancers account for 30 to 50 per cent of all childhood CNS tumours, with approximately 140 Australian children diagnosed annually. [28, 29] While 90 per cent of children with pLGG survive 10 years or longer, undergoing treatment at a young age often results in lifelong morbidities and impaired quality of life. [30]

Treatment options are limited. Surgical resection is often impossible due to the location of tumours in the brain. Chemotherapy is the next-best option, if it is feasible for the type of tumour. It will likely induce significant short- and long-term toxicities and morbidities. [31] Radiation therapy is generally avoided due to the risk of damaging healthy brain tissue. [31]

Some forms of pLGG do not respond to known treatments, increasing reliance on clinical trials:

> *"Families and patients need regular and good access to clinical trials, which are core business for children with cancer. However, support for clinical trials in children is lacking, with 60 to 70 per cent of trials funded by non-profit organisations. Investment in childhood cancer and care can only improve long-term survival and survivorship outcomes for patients, families and society."*
>
> **- Dr Jordan Hansford, Paediatric Oncologist, South Australia**

This report focuses on adults with IDH-mutant glioma. However, the need to invest in clinical trials, treatments and support children with pLGG and their families should not be forgotten.

A **LONG DISABLING ROAD**

As a chronic, incurable brain cancer, IDH-mutant glioma is challenging to diagnose, with disabling symptoms that vary between patients and throughout the course of the disease.

Slow cancer growth is challenging for diagnosis

Early detection and timely intervention are difficult because tumour growth is slow and persistent, at approximately 3.5mm per year. [32] As they progress, tumours typically damage areas of the brain responsible for speech, movement control, vision, sensation and language processing. [32] This damage may go unnoticed for years due to the brain's neuroplasticity (its ability to reorganise and rewire), which compensates for increasingly impaired function. [32] As a result, symptoms often emerge after significant damage has already occurred.

Following diagnosis, patients often enter a "watch and wait" phase, also known as active surveillance. During this time, the tumour is monitored through regular imaging to assess progression. While this approach avoids the immediate risks of invasive treatment, it creates significant emotional stress. [33] Many patients experience "scanxiety", an overwhelming fear and anxiety before each routine scan, as they await news on potential tumour progression. Patients may cycle between rounds of active treatment and surveillance numerous times, adding psychological strain to an already challenging journey.

A tale of two diagnoses

The variability of IDH-mutant glioma gives rise to two distinct diagnostic pathways, shaped by how the disease presents in patients. The first, the 'acute pathway', is typically triggered by a sudden and alarming event, such as a seizure, discernible motor impairment or loss of consciousness. Such events often result in an emergency department visit, where initial assessments are conducted. [34] After symptoms are stabilised, the patient is referred to a neurosurgeon for further consultation. Advanced imaging and evaluations by the neurosurgeon often leads to a diagnosis within a relatively short period. [21]

In contrast, the 'insidious pathway' develops more gradually, with symptoms such as persistent headaches, mental tiredness, fatigue, sleeping difficulties, or nausea. These symptoms often do not prompt immediate concern, leading to delays in seeking medical advice. Patients may initially consult a GP, who may not immediately suspect a serious underlying condition. [34] As symptoms persist over time, repeated medical appointments and inconclusive assessments are likely before an MRI is typically ordered, revealing the abnormality. The patient is then referred to a neurosurgeon for further evaluation and management. This pathway often takes significantly longer to reach a diagnosis. [21]

While these pathways vary in how patients reach a diagnosis, they represent the beginning of a much larger and more complex journey, as the debilitating effects of IDH-mutant glioma become increasingly apparent.

A gruelling set of symptoms emerge

Cancers in our brain, our "control room", cause debilitating cognitive, neurological, psychosocial and physical symptoms that affect every aspect of life. [35] Some of these are depicted in Figure 3. Neurologic symptoms, such as headaches and seizures mark the beginning of the diagnostic journey, but they often progress far beyond to include changes in behaviour, personality, speech, and vision. [3, 36] Increasing cognitive dysfunction is comparable to a traumatic brain injury, challenging executive abilities, decision making, problem solving, focus and memory. [37-39] Processing information becomes taxing, and people may experience noise sensitivity and impaired social cognition. [8] Behavioural problems also arise, including disinhibition, irritability and anger, affecting relationships and isolating a person with IDH-mutant glioma from support systems. [8]

> *I have short term memory deficits, have little sense of days and time passing, do not recognise new people, so I do not create relationships. I am more reactive to emotional hurts and feel a change in my tolerance as the stimulation of the world is overwhelming. I never could have imagined the daily difficulties you face with a disability. I am treated differently by people I know and strangers.*
>
> **- Lisa, 41, Victoria, diagnosed with Astrocytoma in 2018**

Tumour locations in the brain and their symptoms

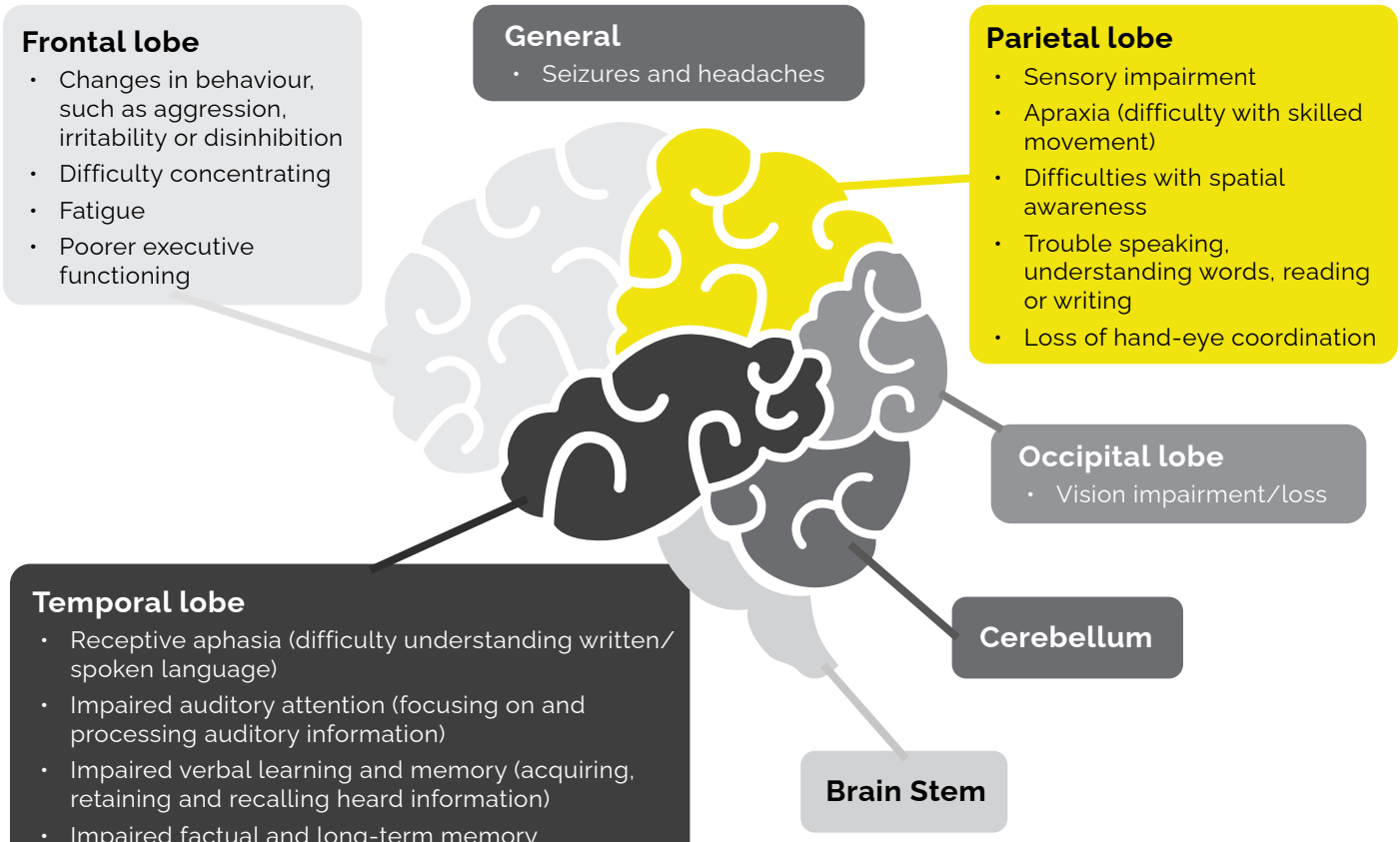


Figure 3: Impacts of glioma in different areas of the brain

Source: Evohealth [3, 8, 40-42]

Psychosocial health is severely impacted

Living with this chronic cancer and its symptoms takes its toll on psychosocial health, affecting mental, emotional, social, and spiritual well-being. This condition disrupts many aspects of life (Figure 4) and can have far-reaching consequences, including:

- **Fatigue:** Common and debilitating, fatigue often results from both the disease and its treatments. [43]
- **"Scanxiety":** The fear and uncertainty surrounding tumour recurrence and ongoing disease management often worsens fatigue. This fear also intensifies depression (reported in up to 90 percent of patients) and anxiety (reported in up to 40 per cent). [36, 37, 44] Patients frequently experience "scanxiety" during the "watch and wait" phase as they anxiously await test results.
- **Sexual dysfunction:** Poorly reported but significant, sexual dysfunction affects both men and women. This limits physical intimacy, affecting mental health and relationships, which, in turn, leads to greater emotional stress. [45, 46]
- **Neurological symptoms and daily living:** Seizures and other neurological symptoms compromise daily activities, including but not limited to driving. [36] The deterioration of hand-eye coordination, motor skills, and balance can eventually result in the loss of independence for basic tasks such as dressing, showering, eating, or moving around. [36]
- **Work and financial impacts**: Cognitive decline and chronic fatigue often make employment impossible, leaving individuals unable to financially support themselves or their families. [47] This loss of purpose and stability adds to the disease burden.
- **Dependence on carers and family:** As independence diminishes, patients increasingly rely on carers and family members, who often face significant emotional, financial, and physical burdens. [48]

> *I try to remain upbeat, but sometimes it is very difficult. My husband has noticed the change in my disposition, and it makes him sad and depressed as well.*
>
> **- Fiona, 34, Queensland, diagnosed with Oligodendroglioma in 2017**

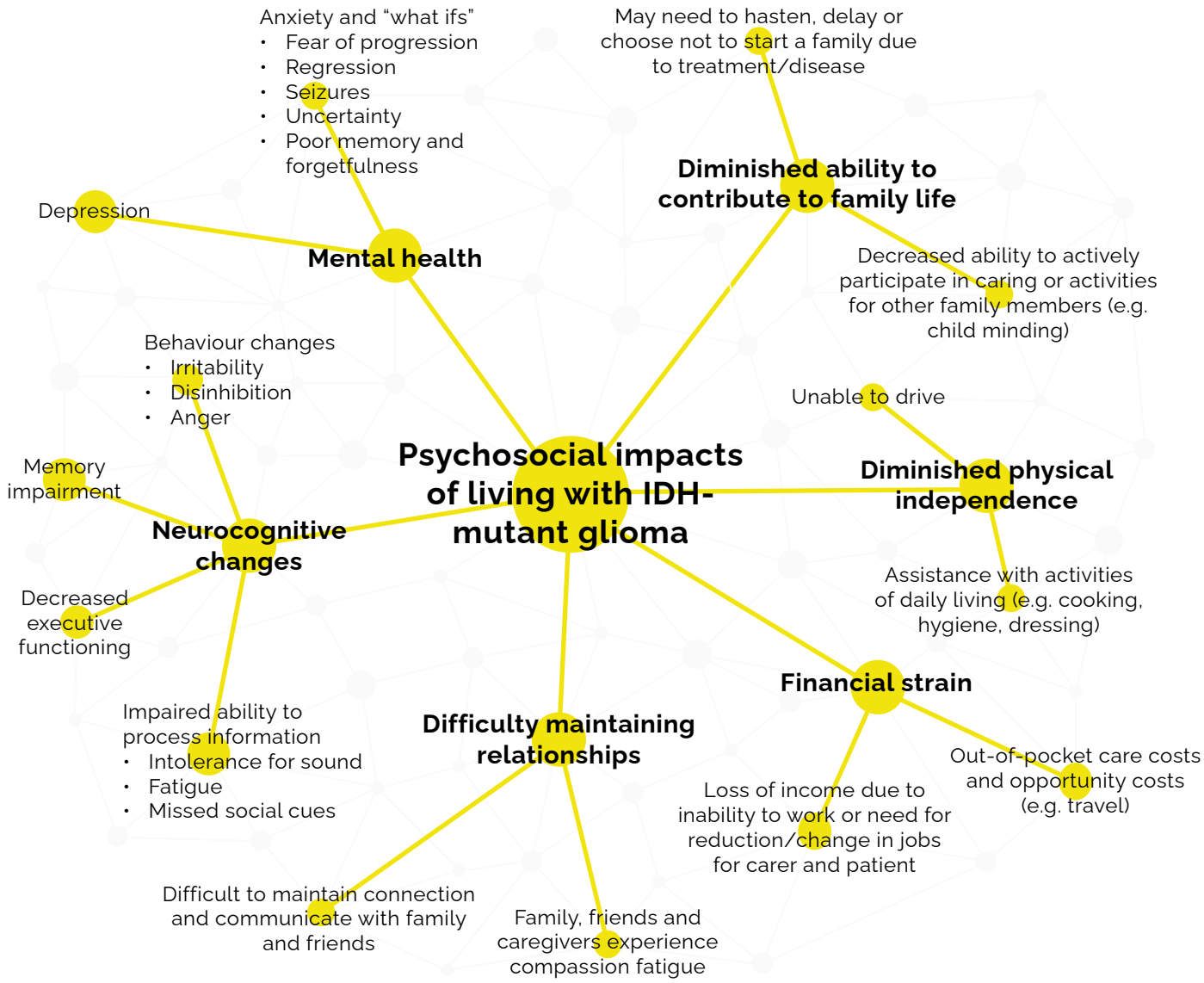


Figure 4: The complex psychosocial web of IDH-mutant glioma *Source: Evohealth [3, 8, 9, 36, 39-44]*

There is no fixed pattern to the presentation of these symptoms; some may come and go for a brief time, others may prevail for extended periods. Each tumour is unique and unpredictable in its progression, symptoms, and prognosis, bringing its own challenges. What can be predicted, however, are the significant quality of life impacts for the usually young and active people affected by this disease, which will stretch over years, or even decades.

A continual decline in quality of life

This disease is life-altering, and its relentless progression, treatments that cause harmful side effects, and unpredictable symptoms leads to a steady erosion of quality of life. Patients often face this decline in relative isolation, navigating limited engagement from healthcare providers during periods of disease stability and strained personal relationships as 'compassion fatigue' and the drain of managing symptoms takes their toll. This growing sense of disconnection magnifies the emotional and psychological weight of their incurable cancer, leaving many to feel forgotten.

People with IDH-mutant glioma live in a state of constant uncertainty, fearing cancer recurrence and the trauma of debilitating treatments. [44, 49] Over time, symptoms such as extreme fatigue, emotional distress and other health issues build up, causing quality of life to decline more severely than for people with other cancers or chronic conditions. [47] Despite this, their emotional and psychological support needs often go unmet. [17]

> *"The impact on my overall well-being cannot be understated. The combination of cognitive difficulties and the loss of cherished activities has created a sense of imbalance in my life. I often feel a lack of purpose and struggle to find fulfillment in other areas, which weighs heavily on my mental health."*
>
> **- Stephen, 45, Tasmania, diagnosed with Astrocytoma in 2015**

The toll of IDH-mutant glioma extends beyond medical treatment to every aspect of life, creating a cascade of challenges that further isolate patients. Loss of independence, fractured relationships, financial strain, and a diminished sense of purpose combine to trap patients in a cycle of isolation and dependence. For these Australians, the journey is not just one of survival but of enduring a life that feels progressively smaller, disconnected, and unsupported.

TUMOUR CONTROL OR QUALITY OF LIFE – **CHOOSE ONLY ONE**

No cure for IDH-mutant glioma exists. Available treatment options impose a difficult choice between better tumour control or maintaining cognitive function, with long-term consequences to quality of life. [6]

Differences in tumour type and location means treatment will vary for each patient, however the approach generally includes surgical resection, chemotherapy and radiation therapy. [3, 5] Each of these treatment approaches and their associated risks and side effects are summarised in Table 1.

Treatment	Description	Risks and side effects
Surgery 	• Surgical resection to debulk the tumour. [50] • Often at beginning of treatment and multiple times over the treatment journey as tumours recur. [3]	• Ongoing seizures, stroke, epidural haematoma and wound infections. [3] • Exacerbate neurological deficits, affecting motor skills, sensory perception, speech, vision, and induce behavioural changes. [3]
Chemotherapy 	• Chemotherapy to stop or slow cancer cell growth, which can be administered orally (e.g. tablet) and intravenously. Either alone or as an adjuvant to other therapies. [51] • May be repeated three to four times across the treatment journey.	• Damage to blood cells (neutropenia, anaemia and thrombocytopenia), liver function, allergic reactions, fatigue and nausea or vomiting. [3]
Radiation therapy 	• High doses of radiation to shrink tumours by damaging cancer cells. [52] • Limited to patients at high risk of early progression despite surgery. • Used on its own if resection is not possible, and can be used in recurrent IDH-mutant glioma. [3]	• Long-term side effects on cognition, quality of life and fatigue. [3] • Radiation-induced brain injury causes cognitive and neurological deficits including dementia, executive dysfunction, and impairments in memory and attention. [37, 53, 54] • Risk of adverse neurocognitive effects increases with frequency and doses of radiation therapy. [53]

Table 1: Common treatment procedures for IDH-mutant glioma *Source: Evohealth*

These treatment options require patients to make complex, highly consequential decisions in a trade-off between tumour control and their long-term neurological health. [6] Efforts to achieve better tumour control during surgical resection can damage healthy brain tissue and create further deficits. [55] Radiation therapy, which is all-but-necessary for patients who face a high likelihood of recurrence, and chemotherapy carry the risk of long-term toxicities and cognitive impairment. [55] Without a cure, the goal of this balancing act is to prolong survival while maintaining quality of life. [4] The need to make these trade offs, with some form of personal impact awaiting in any direction, puts patients and carers in a highly invidious position. To improve lives, we need better treatment options.

FACING THIS **CHRONIC CANCER HEAD-ON**

IDH-mutant glioma is a relentless and chronic cancer that profoundly impacts young Australians in their most productive years, reshaping their lives and futures. Eroding health slowly and unpredictably, it imposes immense physical, emotional and financial burdens on patients and their loved ones.

These burdens are compounded by a lack of progress in improving diagnosis and treatments, a lack of psychosocial support and systemic gaps in our health system that leave many patients and carers navigating their journey alone. Each of these challenges will be reviewed in depth in the following section of the report.

1. Little progress in diagnosis, treatment and research

Despite significant advances in cancer therapies for other brain cancers, little has changed for Australians living with IDH-mutant glioma. For those impacted by this chronic cancer, the absence of meaningful progress and advancement towards a rapid diagnosis and cure compounds the burden and emotional toll of this disease.

Further diagnostic advancements are needed

Diagnosis of IDH-mutant glioma remains reliant on older technologies, including computed tomography (CT) and MRI, followed by molecular studies on the tumour after resection. [3] A cancer diagnosis is unlikely until other conditions have been ruled out and brain imaging occurs. This imaging is repeated throughout the patient's lifetime (up to every three months) to monitor disease progression, taking significant time and exposing patients to additional radiation. While patients with other cancers now benefit from less invasive blood biomarker studies to aid in diagnosis and monitoring of treatment efficacy, no such tool yet exists for IDH-mutant glioma. [56]

Some promising advancements have been made, however. The introduction of molecular studies to determine IDH mutation status has enhanced diagnostic precision and prognostication, providing a critical step forward. International research published in 2024 shows promise for identifying IDH-mutant glioma markers in blood tests, signalling hope for better diagnostics. [57, 58] Yet, for many patients today, the benefits of this research will remain unrealised due to the lead times needed to translate it into practice.

Hope is on the horizon

As outlined above, the current cornerstones of treatment for IDH-mutant glioma (surgery, chemotherapy and radiation therapy) are not curative, must be repeatedly endured and carry substantial risks and side effects (Table 1).

There have, however, been some promising developments. Molecular oncology has identified the IDH mutation as a critical driver of malignancy, paving the way for innovative therapies. [59] This has lead to the trial and development of IDH-mutant inhibitors, a novel class of treatments to become available for IDH-mutant glioma in recent years. In a 2023 clinical trial, inhibition of the mutant IDH enzyme was shown to improve median progression-free survival by 11.1 months to 27.7 months, and improve the time to next intervention, including additional chemotherapy. [2] The first of these therapies was registered on the Australian Register of Therapeutic Goods (ARTG) for the treatment of IDH-mutant diffuse glioma in September 2024, with others in clinical development. [60] The emergence of new treatments signals hope for more precise, less damaging treatments in the future.

Research will need to support discovery and trials for more treatment options that halt disease progression with minimal side effects. Australian patients will then need affordable and equitable access to treatments with proven safety and efficacy. Unfortunately, a scan of current trials for new treatments in Australia reveals most trials for brain cancer focus on paediatric patients or GBM, both of whom will also traditionally receive more research funding. Only two clinical trials for IDH-mutant glioma drug therapeutics are actively recruiting in Australia[1], both investigator-led and funded through federal and state grants. [12, 13] Beyond these, there is no further investment or trials focused on IDH-mutant glioma.

Only **two clinical trials** currently available in Australia investigating treatment options for IDH-mutant glioma. [12, 13]

Insufficient research funding is stagnating progress

Australia's investment in cancer research remains heavily skewed towards high-prevalence diseases, which benefit from greater public awareness and advocacy. In stark contrast, IDH-mutant glioma, though rare, imposes a disproportionately high burden on patients, families, and the healthcare system, which highlights the need for it to receive more attention. Historically, funding for all brain cancers has accounted for less than five per cent of all federal government cancer funding, a glaring inequity correlating with poorer patient outcomes. [61] This chronic underfunding has widespread effects. Over the past 30 years, the five-year survival rate for all cancers has improved dramatically from 50 per cent to 70 per cent. [62] For brain cancers, this increase has been a mere two per cent, now standing at just 22 per cent. [63] The neglect of brain cancers extends beyond advances in treatments; it has stymied progress in diagnostics and treatment, while leaving critical psychosocial and other support needs unaddressed.

[1] Based on a desktop scan of actively recruiting clinical trials in Australia, including the Australian New Zealand Clinical Trials Registry, for IDH-mutant glioma or low-grade glioma on 22 November 2024.

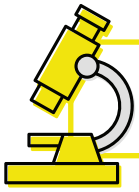
Increasing investment in research is not just about addressing the present; it is about securing a better future for generations to come. While more aggressive cancers draw attention and funding, IDH-mutant gliomas are often overlooked, leaving patients without the breakthroughs they urgently need. Investing in research for IDH-mutant gliomas means investing in hope, innovation, and lives.

- Associate Professor Santosh Poonnoose, Neurosurgeon

While recent funding increases to brain cancer research through initiatives like the Australian Brain Cancer Mission offer some hope, they do little for IDH-mutant glioma. [64] Since the ACBM's inception in 2017, the Commonwealth has invested over $50 million in brain cancer research. However, **only one project** directly related to IDH-mutant glioma has been funded, receiving just over $500,000. [10]

Similarly, of the additional $76 million pledged to Australian Brain Cancer Mission through Funding Partners (e.g. not-for-profit organisations, tertiary research centres and health services), only one IDH-mutant glioma specific project has been funded for $100,000. [14] Outside of the Australian Brain Cancer Mission and Funding Partners, one additional clinical trial for IDH-mutant glioma received $1.9 million in 2022 under a separate Medical Research Future Fund initiative. [10]

Some progress in trials and research for other brain cancers will likely benefit people living with IDH-mutant glioma, however, the longevity and progressive disability of the disease, along with the IDH marker make it unique and deserving of its own funding and focus.



Of **$126+ million** available in the Australian Brain Cancer Mission, IDH-mutant glioma specific projects have received **0.47 per cent of funding.** [10, 14]

The lack of focussed research funding underscores the urgent need for targeted investment in IDH-mutant glioma research. Without focused funding, Australia risks failing this vulnerable cohort who too often are forgotten in our health system.

Increased and equitable funding in research is critical to fostering innovation, improving patient outcomes, and ensuring no one with IDH-mutant glioma is left behind.

With the Australian Brain Cancer Mission, we have this vehicle to help address inequity in brain cancer for Australians, but it's clear that there is simply not enough research being funded for people with this brain cancer. There needs to be more funding specified for IDH-mutant glioma in the Mission. The people with this cancer are our family, friends, coworkers, neighbours – they deserve better. They deserve more hope.

- Sam McGuane, Executive Director. Carries Beanies 4 Brain Cancer Foundation

Lack of targeted research into IDH-mutant glioma hinders progress in diagnostics and treatment options. This gap delays earlier detection and perpetuates reliance on harmful and less effective treatments.

2 The Australian health system is not designed to support chronic cancer care

Patients with IDH-mutant glioma will repeatedly move in and out of the health system throughout their lives. This creates significant challenges when required to navigate and advocate for their needs in a fragmented system designed predominantly for acute cancer management.

No optimal care pathway

No optimal care pathway for IDH-mutant glioma exists in Australia. This is in contrast to the care pathway for high grade glioma, which has been published and updated in recent years. [65] Such pathways are essential as they include information and guidelines on key diagnostics and treatments, referral options, and checklists to support best-practice and patient-centred care, from prevention and early detection through to end of life care. [65] They are important for both clinicians and patients. Without a clearly defined care pathway for IDH-mutant gliomas, patients and carers face further uncertainty dealing with an incurable disease over many years.

Uncertainty in the care journey creates information and support access barriers

The inherent uncertainty of IDH-mutant glioma imposes barriers to accessing timely, accurate information and appropriate support services. Individuals must advocate for their own needs, a daunting task within Australia's complex multijurisdictional healthcare system. [66] Patients, carers and families struggle to navigate care pathways due to the absence of documented resources outlining a "typical" patient journey and appropriate care.

Tumour-related cognitive dysfunction makes this particularly challenging, leaving patients uniquely disadvantaged in managing their care. Variability in disease presentation further complicates their efforts to identify the right information and support services. [17]

This is compounded by the under-representation of this cohort in research programs. Patients and carers struggle to find and interpret reliable information. As cognition degenerates, all of these factors become more challenging, requiring substantial external support. Addressing these gaps requires a cohesive approach to streamlining care pathways and making resources easily accessible.

People with IDH-mutant glioma feel forgotten

People with IDH-mutant glioma under active surveillance report feeling forgotten by the system, as they experience less contact with clinicians compared to those with more aggressive cancers (e.g. GBM). They have fewer opportunities to discuss how their cancer is progressing, despite new symptoms emerging or existing issues worsening.

Combined with 'compassion fatigue' from friends and family, patients feel isolated, and quality of life often declines further.

> *There's not much follow-up from the health system. When [patients] are not in active treatment, they're in limbo. We hear regularly that, 'unless I call my oncologist, my neurologist, my clinicians directly, I will go six months before hearing from anyone'.*
>
> **- Bec Mallet, CEO and Founder of Peace of Mind Foundation, and brain cancer patient advocate**

Brain Cancer Care Coordinators offer the answer, yet access is limited

Brain cancer care coordinators[2] (BCCCs), who are experienced nurses, social workers, psychologists, or occupational therapists, play an essential role in supporting people through brain cancer care. [16] They manage treatment, surveillance, neurocognitive disabilities, psychosocial challenges, comorbidities, medications, and palliative care, all of which is complicated by the variability of brain cancer presentations. [67]

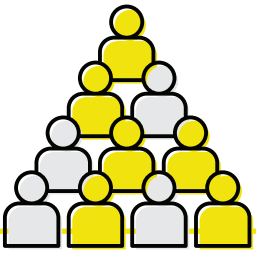
> *Brain cancer care coordination demands specialised expertise due to the unique complexity of this disease. Comparable tumours just millimetres apart can mean the difference between requiring assistive care or not.*
>
> **- Medical and radiation oncologist, Newcastle**

These coordinators guide patients through the healthcare system and advocate on their behalf with all specialty clinicians involved in the patient's care. Their role reduces health system utilisation, with a recent study demonstrating a 24 per cent reduction in hospital length of stay for patients supported by a BCCC. [15] They even support and coordinate patient applications for National Disability Insurance Scheme (NDIS) funding, a process notoriously difficult to navigate even for those with undiminished cognition.

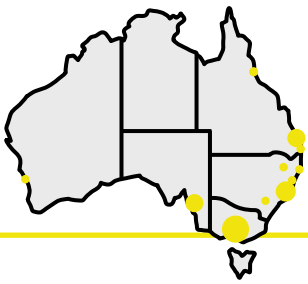
However, access to BCCCs is limited. There are only 29 BCCCs nationwide, working in 20.6 full-time equivalent positions. [67] This is not enough. Almost a third of BCCC roles are funded for multiple cancers, further straining their capacity to focus on a population with highly complex and unique needs. [67]

With 2,000 new brain cancer diagnoses annually, this equates to one BCCC for every 69 patients, without taking into account those who require long-term care, such as IDH-mutant glioma patients. [64]

[2] A brain cancer care coordinator may also be known as neuro-oncology care coordinator, brain cancer nurse navigator, neuro-oncology clinical nurse consultant, or other variants. As this role is not centrally funded, there is no uniformity in the role title, which further confuses care accessibility for patients, carers and family.



There are **only 29 BCCCs nationwide**, working in just **20.6 full-time equivalent positions.** [67]



Nine out of 10 BCCCs are based in major cities on the east coast of Australia. [67]

Geography exacerbates accessibility issues. Nine out of 10 BCCCs are based in major cities on Australia's east coast, with none in Tasmania or the Northern Territory. This leaves regional, rural and remote patients, or simply those on the 'wrong' side of the country out of luck. For IDH-mutant glioma patients, who often face cognitive and physical limitations that restrict travel, this postcode lottery presents an additional challenge to accessing support.

> *Brain cancer, unlike other cancers, has received little to no Commonwealth funding for survivorship – ever. Current BCCCs are not funded by the Commonwealth, reinforcing the invisibility of this diseases and its impacts. This needs to change.*
>
> **- Craig Cardinal, Chair of Brain Tumour Alliance Australia and the Australian Brain Tumour Collective**

The under-resourcing of BCCC roles is a systemic issue. At least a quarter of these positions are fully or partially funded by non-profit organisations rather than sustainable government funding. Furthermore, the Australian Cancer Nursing and Navigation Program (ACNNP), established in 2023 to oversee cancer care coordination roles nationally, failed to integrate the complex survivorship needs of brain cancer patients, including those with IDH-mutant glioma. [67, 68] This oversight underscores the urgent need for system-level investment to expand and ensure sustainable access to BCCCs.

Current underfunding of BCCCs is limiting access for patients with IDH-mutant glioma. This lack of access leaves patients, carers, and families without the necessary support to navigate the brain cancer survivorship journey. Without increased funding, many individuals will continue to struggle to advocate for their care and support needs effectively.

3 Psychosocial support needs are overlooked and unmet

In the absence of curative treatments, effective psychosocial care offers a vital lifeline for patients, carers, and families. Despite its importance, psychosocial support remains poorly integrated across the care continuum, leaving patients and their families struggling to access it.

The need for psychosocial care is common but not prioritised

The lack of psychosocial support is a critical unmet need for patients and their families. [17] Untreated psychosocial distress impacts patients' capabilities, quality of life and their length of survival. A longitudinal study identified IDH-mutant glioma patients who were depressed experienced significantly shorter survival times (three to six years), compared to their non-depressed peers (10 to 12 years). [69] A similar trend was observed in those who experienced post-traumatic stress disorder, anxiety and depression following craniotomy which increased their five-year mortality risk 2.46-fold. [49] Despite this, the health system's de-prioritisation of psychological distress is evident, with psychological needs relegated to the appendix of optimal care pathways for both high-grade glioma and head and neck cancers. [65, 70]

Similarly, sexual health is often overlooked as a key component of psychosocial wellbeing. Research identifies disruptions to sexual health provoke relationship strain, heighten anxiety, depression, and diminish quality of life. [71] A recent review identified just three studies investigating sexual dysfunction and quality of life in IDH-mutant glioma patients. [71] Given this, it is unsurprising that 60 per cent of neurosurgeons never discuss sexual health with glioma patients. [72] The neglect of this critical aspect of holistic care is a further blow in patients' ongoing battle to maintain wellbeing. [46]

A lack of baseline and ongoing assessments of psychosocial needs limit effective monitoring and management

Elevated distress in IDH-mutant glioma patients often remains undetected and untreated. [44] In part, this is because baseline assessments of psychosocial factors, including cognitive, emotional and physical health are not routinely performed, leaving clinicians struggling to detect and address changes as the disease evolves. [17, 44] Similarly, ongoing monitoring is also essential but rarely performed. This is further complicated by the patient's reduced ability to communicate or recognise changes in emotional regulation, which may lead to behavioural problems, aggression, and challenges with social interactions. [36, 39] Failing to measure, monitor and respond to changes in social cognition increases the risk of poor social participation and loss of relationships. [8]

> *Baseline neuropsychological assessments are absent for this patient group, despite the critical need to understand and address their almost-certain cognitive decline over the course of their disease.*
>
> **- Professor Haryana Dhillon, Behavioural Scientist**

As numerous studies have indicated, regular assessments for psychosocial support needs must become a standard component of care to ensure patients and their families have the information to navigate the challenges of the disease. [18, 43, 44, 49, 55, 73]

Access to care and support is limited

Even when psychosocial support needs are recognised, access remains difficult. A recent study of the Australian Tele-MAST program found psychosocial care delivered via telehealth can reduce symptoms of depression and anxiety, improve quality of life and save $4,327 in costs when factoring in Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS) and out-of-pocket expenses. [18, 20]

Rehabilitative care is another cornerstone of psychosocial support, playing a crucial role in maximising function, enhancing quality of life, and reducing long-term care needs. [74] Rehabilitation is just as effective in restoring function for brain tumour patients after neurosurgery as it is for stroke recovery. [21] However, despite the benefits, poorly defined referral pathways and limited clinician awareness continue to hinder patient access.

Psychosocial care tailored for people with cancer, also known as psycho-oncological care, remains inconsistent, difficult to access, and often prohibitively expensive. While psycho-oncology and rehabilitative services can be bulk-billed under the MBS, long waiting lists, fragmented integration into oncology care, and unclear referral pathways limit their availability. [18] Private services exist, but their high costs put them out of reach for many patients. Additionally, workforce shortages mean there are too few psycho-oncology specialists to meet the growing demand. [19]

> *"In general, neuropsychology is not accessible and doesn't have an MBS item number, so patients can only access these crucial services privately or through publicly funded clinics. There are very few of these clinics and they all have extensive waiting lists."*
>
> **- Professor Haryana Dhillon, Behavioural Scientist**

These problems are worse for those living in rural and remote areas. Most psycho-oncology services in Australia are hospital-based in capital cities, particularly on the east coast. Although telehealth offers a promising alternative, inconsistent high-speed internet access across Australia remains a barrier. [75]

Failing to adequately address psychosocial care and rehabilitation needs is leading to poorer quality of life for patients, carers, and families. The lack of baseline assessments and ongoing monitoring means the changing needs of patients, and impacts to their loved ones, are often overlooked. This is exacerbated by unclear referral pathways and inequitable access to these services across the country.

From doctor to patient: a life forever changed

Told by Hannah, aged 52, Victoria, diagnosed with Astrocytoma in 2001

For many years, I led a fulfilling life as a GP, deeply dedicated to my patients and my work. My career was more than a job—it was my passion and purpose. I balanced my demanding profession with raising a family, socialising, travelling, and enjoying an active lifestyle. That life came to a sudden halt when I was diagnosed with a brain tumour, specifically a grade two astrocytoma.

The tumour and subsequent surgical interventions and treatments have left me with a permanent brain injury. I now have lifelong brain damage, frequent seizures and physical disability. These changes have profoundly impacted my life, stripping away my independence and altering my ability to perform even the most basic tasks.

Losing my career was devastating. Being unable to work or drive has left me feeling disconnected from the world and reliant on others for nearly every aspect of my daily life. Tasks like showering, dressing, cooking, cleaning, and even moving around the house are impossible without assistance. I am at high risk of falls, and my frequent seizures mean someone must always be nearby in case of an emergency. Without help, I am confined to bed, unable to manage basic human needs.

Perhaps the hardest part of this journey has been losing my independence and the isolation that comes with it. I once cared for my family, but now I am the one in constant need of care. This role reversal has been deeply upsetting and will shape the rest of my life. The lack of physical activity and social engagement has taken a toll on my mental health, leaving me fatigued and depressed. I now rely on antidepressants to help manage the emotional burden. Social interactions, once a source of joy, are now limited and I miss the face-to-face connections I once cherished. Phone calls with friends provide some solace, but I long for the ability to engage more fully with the people and activities I love.

My husband's support is crucial. However, the immense physical and emotional burden he carries affects us both, and the rest of our family. Without any community support, the challenges we face have only intensified. My medical team, including my GP and neurologist, provides essential care, but I need better community support to address my daily needs. Looking ahead, I hope for the assistance required to improve my quality of life, regain some independence, and restore a sense of dignity and hope to my life.

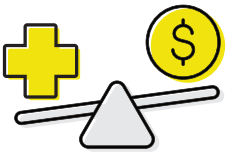
4 Carers and families also bear the burden

As IDH-mutant glioma inevitably progresses, so too do the care and support needs of the patient. Family, partners and close friends typically assume the informal carer role. a challenging responsibility to hold as they watch their loved one's health deteriorate. [9] This role becomes increasingly complex and demanding over time as the disease advances, yet the effects on carers and families remains poorly understood and insufficiently supported by the Australian health system.

Complexity of care increases as the disease progresses

The care needs of a person living with IDH-mutant glioma change considerably over time, as does the role of the carer. These may include:

Day to day caregiving: Managing medications, scheduling and attending appointments and overseeing treatments, physical assistance, and communicating and advocating on behalf of the patient as their cognition declines. [9]



Practical and household responsibilities: Driving and transportation, becoming the sole income earner, parenting duties, managing household tasks and finances. [9, 76]

Emotional and psychosocial support: Responding to behavioural changes, supporting mental health, manging family and other social dynamics. [9]

These needs are time consuming. In 2024, informal carers of patients with IDH-mutant glioma provided 1,814,124 hours of unpaid care. [1]

1,814,124 hours of unpaid care provided by informal carers in 2024. [1]

As the disease progresses and care becomes more complicated, carers are often left feeling unprepared and overwhelmed. [9] There is little information about the disease and what to expect as it progresses, despite research indicating that access to such information helps carers cope and navigate the healthcare system more effectively, reducing psychological distress for them and the patient. [77] Access to other services, such as respite care. counselling services, and financial assistance programs is also lacking.

Changes in personality can be traumatic for family

Early behaviour and personality changes commonly seen in IDH-mutant glioma can be subtle, with emerging uncharacteristic anger or irritability being an example. [8]. Changes can worsen over time, becoming distressing for carers and family members to witness and manage. [78] This extends deeply into the lives of carers and families, straining relationships and reducing the willingness of extended family or friends to share in caregiving responsibilities, which returns much of the burden to already-stretched primary carers. [9]

The emotional toll of caring

The impact on myself and my children has been significant. [My husband] used to be fun, happy, cheeky, capable and dependable. He is now tired, frustrated, short-tempered, dependent and unpredictable. He gets frustrated very easily and often escalates into a meltdown, where he cries, smashes things or hurts himself out of sheer frustration. I try not to leave the teenagers with him in the house alone in case he has a meltdown. His needs require more support than he currently receives.

It is exhausting and pushes me to my limits some days. I experience anxiety and stress from [my husband]'s behaviour and I find it hard to cope when his behaviour escalates into violence and becomes damaging.

- Leila, 45, cares for Leo, 45, Queensland, diagnosed with Oligodendroglioma in 2021

The impacts of caregiving are poorly recognised

The demands of caregiving are well-documented in cancer research, however, few studies address the distinct and heightened strain associated with IDH-mutant glioma. [79] Common experiences include exhaustion, depression, anxiety, disrupted sleep, physical health strain and burn-out, with flow-on effects to relationships and social isolation. [9] While these experiences may be typical in cancer cases, the evidence indicates this burden as growing, unmet and more severe for IHD-mutant glioma. [80] Severe fatigue, for example, was reported in 63 per cent of IDH-mutant glioma caregivers in one study, a rate higher than commonly found in research in other cancers. [79]

As with patients, there is a demonstrated need to integrate psychosocial monitoring for caregivers and ensure they have access to the support they need to maintain their quality of life. [76]

I live with my elderly mother who tries to help me, but she has health issues too. It's physically very difficult for her, and puts a lot of pressure on her, as well as our relationship.

- Lisa, aged 41, Victoria, diagnosed with Astrocytoma in 2018

The financial burden of care

The economic costs of caregiving are also poorly recognised. Informal carers, often family members in their prime working years, may sacrifice their own professional life to provide support, restricting their income earning abilities. The national productivity loss for carers supporting a person with IDH-mutant glioma is estimated at $71.6 million each year. [1] When combined with the $74.8 million annual productivity loss of people living with IDH-mutant glioma, the total household income loss is estimated at $146.4 million per year.

On average, individual households supporting a person with IDH-mutant glioma forego $53,460 of income each year. [1] This loss compounds financial instability for households which are already stretched thin; particularly for young families raising children under intensified financial, emotional and physical strain. Reduced earning capacity and household wealth, including contributing to superannuation or pension funds, has serious long-term consequences.

~$71.6 million per year **productivity loss for carers** supporting a person with IDH-mutant glioma. [1]

The estimated financial burden on households amounts to **$53,460** per patient per year. [1]

Accessing financial support to bridge this gap is challenging for both patient and carer as IDH-mutant glioma is not officially recognised under pathways maintained by the Department of Social Services (DSS) or NDIS. Without a streamlined application process to follow, the complex paperwork and nuanced disability criteria requires professional expertise to navigate – an expertise most carers do not have.

The rules governing the availability of the Carer Payment are impractical, with a limit on paid employment of up to 25 hours per week and financial penalties applied if this limit is exceeded. [81] Carers unable to meet these rules may be eligible for the Carer Allowance instead if their income permits, however this payment is equivalent to just $76.75 per week. [82] In the face of steadily increasing treatment and supportive therapy costs, coupled with the loss of the patient's income, it is unsurprising most carers will try to maintain paid employment where possible.

To provide better financial support for those affected by this invisible disease, access to financial aid for IDH-mutant glioma patients and their families must be improved. [79]

The lack of adequate support for the carers and families of people living with IDH-mutant glioma negatively impacts the quality of life of everyone affected by the disease. Current support is fragmented and fails to address the full range of needs, including psychosocial measures, access to information, resources, and income support.

RECOMMENDATIONS

Australians living with IDH-mutant glioma, along with their carers and families, face significant challenges, including inadequate support, limited research advancement, and a lack of effective therapies. These gaps have left a young and productive population invisible, with far-reaching personal, societal, and economic consequences. The burden of this chronic cancer extends beyond the individual, placing enormous strain on carers, families, and the broader health system.

To address the critical challenges outlined in this report, we propose a series of actionable recommendations aimed at improving outcomes and quality of life for everyone affected by IDH-mutant glioma. Together, they offer a roadmap to change both now and into the future by transforming the care experience and ensuring this invisible population receive the resources and recognition they deserve.

RECOMMENDATION 1

Acknowledge and invest in the long-term treatment, support and research funding needs of IDH-mutant glioma as a chronic cancer within the Australian Brain Cancer Mission.

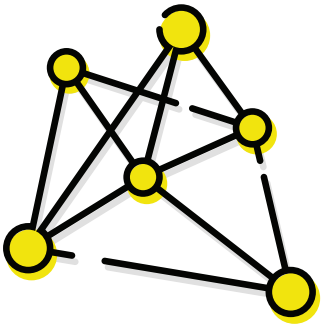
Enhanced quality of life is a key aim of the Australian Brain Cancer Mission, and a fundamental challenge for patients with IDH-mutant glioma, their carers, and families. This young, productive cohort and their loved ones live with the disabling consequences of a progressive chronic cancer for many years before they die. The Mission must be updated to explicitly recognise IDH-mutant glioma, or low-grade gliomas, as a priority cohort for specific investment in its research roadmap. This recognition will encourage greater investment for this invisible cohort so they too may hold hope for better treatments, diagnostic approaches, quality of life and ultimately survival gains. Integrating IDH-mutant glioma into the Mission will raise its profile within the broader cancer care and research landscape, representing a long-term commitment to these Australians.

RECOMMENDATION 2

Recognise IDH-mutant glioma in NDIS and DSS criteria as a condition causing permanent disability to streamline access to financial support for patients living with IDH-mutant glioma, their carers and families.

The financial burden of IDH-mutant glioma is profound, with patients, carers and families facing income loss alongside significant opportunity costs of treatments, ongoing monitoring, and supportive care. Recognition of IDH-mutant glioma under the NDIS and DSS criteria would simplify access to critical financial support mechanisms, including the NDIS and Disability Support Pension (DSP). These supports are essential for managing care costs, accessing innovative treatments or medications, and alleviating financial strain on families. Incorporating all tumour grades and types of IDH-mutant glioma into priority pathways, such as the manifest grant for DSP available to GBM patients, would ensure timely access to these vital supports.

Future improvements to financial support could include early access to superannuation or life insurance payouts, providing patients and families with much-needed funds earlier in the care journey. These measures would help mitigate escalating financial toxicity and aid families managing the substantial economic demands of this long-term chronic cancer.

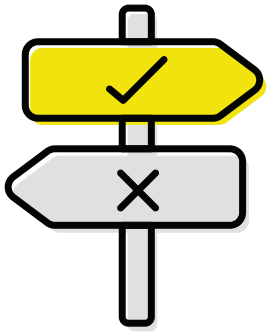


RECOMMENDATION 3

Develop and fund a national BCCC model.

Patients with IDH-mutant glioma have highly complex care needs due to the cumulative and progressive disabilities caused by the tumour and treatments. This necessitates specialist coordination support for patients, carers and family, who must advocate for care and support needs over a long and difficult survivorship. Navigating this journey can feel impossible, as increasing health system interactions, unique care requirements and a fragmented path between treatment and active surveillance make it increasingly difficult to access appropriate care.

A dedicated BCCC model is essential to bridge gaps in care, streamlining support across the continuum, and improving outcomes for patients and their support systems. This national model may benefit from collaboration with the ACNNP, which already funds dedicated nurse coordinator roles across breast, melanoma, lung and prostate cancers to ensure everyone with cancer has access to high quality care. [68] Ultimately, funding more specialists in this primary brain cancer-focused role is essential to provide the sustained, personalised support this invisible population needs.



RECOMMENDATION 4

Develop a consensus statement to define the patient pathway, including treatments, monitoring, supportive care and workforce requirements needed to provide optimal care for Australians living with IDH-mutant glioma.

Australians with IDH-mutant glioma, along with their carers and families, face an uncertain care pathway that lacks adequate integration of psychosocial, rehabilitative, and supportive care, as well as ongoing monitoring and medical treatments. A comprehensive statement is needed to map key therapeutic and supportive inputs across the care journey from diagnosis to end of life support. This statement should ideally:

- outline the ongoing monitoring needs of this cohort;
- describe the treatment options available to them and eligibility for each;
- outline the rehabilitative and psychosocial supports available; and
- identify the clinical professionals, referral pathways and health infrastructure required to deliver each component.

Once the optimal care pathway is agreed upon, the required changes in service delivery, funding arrangements, and workforce can be clearly identified and implemented. With its deep connections to patients and specialists in the brain cancer community, the Australian Brain Tumour Collaborative may be well-positioned to lead this initiative, ensuring the patient pathway reflects long-term and holistic care needs.

RECOMMENDATION 5

Develop a clinician-led submission to the Medical Services Advisory Committee for MBS funding to improve access to rehabilitative and psychosocial care for chronic brain cancers.

This cohort faces substantial and persistent gaps in accessing rehabilitative and psychosocial care, which are essential to managing their long-term disability and maintaining functionality. The integration of physiotherapists, clinical psychologists, neuropsychologists, occupational therapists, and speech pathologists in the multidisciplinary team is critical to addressing these complex needs. Funding this care through the MBS would improve accessibility and reinforce the delivery of consistent, centralised care. This could be delivered through development of a new MBS item number for neuropsychology assessments, or revision of existing MBS items to expand coverage of clinicians in multidisciplinary case consultations, or increased coverage for allied health and clinical psychology.

A clinician-led submission outlining the necessity and benefits of psychosocial assessments and multidisciplinary care is a vital step toward addressing this gap and ensuring equitable access to essential rehabilitative services. This submission should demonstrate the clinical and cost-effectiveness of these interventions, describe implementation into existing services, and address access and equity barriers. [83] Patient and clinician testimonials would further strengthen the case. [83]

Australians living with IDH-mutant glioma have long been overlooked, leaving patients, their carers, and families to face its profound challenges alone. The recommendations outlined in this report present a path to a better future for these Australians, addressing crucial gaps in research, care coordination, clinical and financial support.

By implementing these measures, we can work towards improving survival and quality of life for those affected by this chronic cancer. Together, we can ensure IDH-mutant glioma patients, and their loved ones are no longer unseen or unsupported, fostering a future where care is as enduring as the courage of those who face this disease.

ABBREVIATIONS

Abbreviation	Description
ABS	Australian Bureau of Statistics
ACNNP	Australian Cancer Nursing and Navigation Program
AIHW	Australian Institute of Health and Welfare
ARIMA	Autoregressive Integrated Moving Average
ARTG	Australian Register of Therapeutic Goods
BCCC	Brain cancer care coordinator
BRAINS	Brain cancer Rehabilitation, Assessment, Intervention for survivor Needs
CNS	Central Nervous System
COGNO	Cooperative Trials Group for Neuro-Oncology
COI	Cost of Illness
CT	Computed tomography
DALYs	Disability-adjusted life years
DSP	Disability Support Pension
DSS	Department of Social Services
FTE	Full-time equivalent
GBM	Glioblastoma
GP	General practitioner
IDH	Isocitrate dehydrogenase
LGA	Local Government Area
MBS	Medicare Benefits Schedule
MRI	Magnetic resonance imaging
NDIS	National Disability Insurance Scheme
NHMRC	National Health and Medical Research Council
PBS	Pharmaceutical Benefits Scheme
pLGG	Paediatric low-grade glioma
Tele-MAST	Telehealth Making Sense of Brain Tumour
YLD	Years Lived with Disability
YLL	Years of Life Lost

APPENDIX – **METHODOLOGY FOR THE ECONOMIC ANALYSIS**

Cost of Illness Approach

A Cost of Illness (COI) approach was used to measure the economic burden of IDH-mutant gliomas in Australia. This approach accounted for direct and indirect costs associated with the disease, as well as societal costs, which integrate the burden of disease into the economic analysis.

Direct costs included healthcare expenses such as diagnostic tests, treatments, and long-term care. Indirect costs captured productivity losses, caregiving burdens, and premature mortality. Societal costs were quantified using DALYs, providing a comprehensive view of the impact of IDH-mutant gliomas on patients, families, and society.

Prevalence-based modelling

A prevalence-based approach was adopted to estimate the number of individuals living with IDH-mutant gliomas at any point in time. This method enabled a more dynamic understanding of the disease burden compared to incidence tracking.

1. **Prevalence estimation:**
   - Population forecasts by Local Government Area (LGA) were sourced from the Australian Bureau of Statistics (ABS) and further forecasted using ARIMA (Autoregressive Integrated Moving Average) models to project trends to 2050.
   - Glioma-specific survival rates, stratified by histology, age group, and sex, were obtained from the Australian Institute of Health and Welfare (AIHW). These rates were combined with the population forecasts to estimate prevalence.
   - Survival data were adjusted using linear and Weibull models to address gaps, ensuring alignment with trends reported in glioma-specific literature.
2. **Data validation:**
   - The prevalence estimates were validated against available global glioma data and literature to ensure reliability.

Economic analysis of glioma

1. Direct costs: Direct costs were calculated based on the healthcare utilisation patterns of glioma patients:

- Diagnostic and treatment costs: Included expenses for imaging (e.g., MRI, CT scans), radiation therapy, chemotherapy, surgical interventions, and hospital stays.
- Support services: Covered funding under NDIS for patients under 65, aged care costs for older individuals, and DSP for patients unable to work.
- Costs were differentiated by two healthcare pathways:

1. Acute symptom pathway: High-acuity care for patients presenting with severe symptoms such as seizures, including emergency room consultations and immediate specialist referrals.
2. Gradual symptom pathway: Care accessed through GPs for patients with subtle or gradual onset symptoms, followed by specialist referrals.

2. Indirect costs: Indirect costs captured broader economic losses:

- Productivity losses: Estimated based on patient employment capacity post-diagnosis, adjusted for return-to-work rates and full-time equivalent (FTE) levels.
- Caregiver burdens: Quantified through reductions in work hours among informal carers, monetised using ABS income data.
- Premature mortality: Losses from early deaths were modelled using mortality projections and average annual incomes.

3. Societal costs: Societal costs combined direct and indirect costs with the burden of disease:

- Years of Life Lost (YLL): Calculated using premature mortality estimates, assuming a life expectancy of 83 years.
- Years Lived with Disability (YLD): Estimated using prevalence rates and international disability weights for moderate cognitive impairments.
- Monetised DALYs: DALYs were monetised using a societal willingness-to-pay threshold to quantify the broader economic burden.

Data sources

The analysis relied on the following data sources:

1. Incidence rates and survival data:

- Incidence rates and survival data for gliomas were sourced from the AIHW, stratified by histology, age group, and sex.

2. Population data:

- Population forecasts by LGA were obtained from the ABS and further forecasted using ARIMA modelling.

3. Research funding data:

- Information on glioma research funding was collected from the National Health and Medical Research Council (NHMRC) to contextualise funding allocation relative to disease burden.

4. Employment and income data:

- Employment rates and income data were sourced from the ABS, providing inputs for calculating productivity losses and caregiver costs.

5. Clinical cost inputs:

- Craniotomy costs were based on the AR-DRG B02B Cranial Interventions, Intermediate Complexity from the National Hospital Cost Data Collection (NHCDC) cost weights, AR-DRG version 11.0.
- Costs for imaging (MRI, CT), radiation therapy, and neurology consultations were sourced from the MBS. Out-of-pocket costs were included using the Australian Government's Medical Costs Finder.

- PBS data for temozolomide dosing and pricing were sourced from PBS listings and supplemented with published clinical trial data.

6. Support services and social care costs:

- Average NDIS package costs and the proportion of people with glioma receiving NDIS by grade and tumour type were sourced in consultation with patient advocates.
- Aged care costs were sourced from the AIHW GEN Aged Care Data
- Disability Support Pension costs were sourced from Services Australia data.

7. Indirect cost inputs:

- Return-to-work rates and full-time equivalent adjustments by tumour grade were sourced in consultations with patients, advocates, clinicians, and validated with the expert advisory committee. These rates were multiplied by the ABS average earnings series and applied to stratified age groupings.
- Carer lost wages were sourced from peer-reviewed literature.

8. Societal cost inputs:

- YLD were calculated using prevalence rates and disability weights for motor plus cognitive impairments (moderate: 0.203; severe: 0.542) from the Australian Burden of Disease Study: Methods and supplementary material 2018 (AIHW, 2021). The moderate weight was applied to IDH-mutant grade 2 and grade 3 gliomas, while the severe weight was applied to grade 4 gliomas. This classification was validated in consultation with the expert advisory committee.
- YLL were calculated using premature mortality estimates derived from AIHW life tables, with a standard life expectancy of 83 years.
- Monetised DALYs were estimated using the Australian Government's Value of a Statistical Life Year (VSLY) of $235,000 from the Value of Statistical Life guidance.

Limitations

- While efforts were made to account for differences in treatment pathways and costs across glioma histology and grades, such as incorporating variations in diagnostic and therapeutic approaches (e.g., surgical intervention rates, chemotherapy regimens, and radiation therapy schedules), these distinctions may not fully capture the complexity of care. This variability was addressed to the extent possible using stratified data, literature, and the expertise of the advisory committee members. However, the nuanced differences between histology and grades may result in some underrepresentation of the true costs associated with IDH-mutant gliomas. As a result, the findings presented here are likely conservative estimates of the economic burden.
- The prevalence-based approach relies on assumptions about stability in survival and background mortality trends, which may not fully account for future changes in glioma treatment or prognosis.
- Productivity and caregiving losses might be underestimated, particularly in cases of informal or unpaid care.

This methodology ensures a robust and transparent framework for understanding the economic and societal impacts of IDH-mutant gliomas in Australia.

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