



**BRAIN TUMOUR**  
ALLIANCE AUSTRALIA Inc.  
**1800 857 221**

**MAY 2021**

**BTAA.ORG.AU**



# Survivorship Matters

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

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

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

Cancer Connections (online)  
[www.cancerconnections.com.au](http://www.cancerconnections.com.au)

Email [btaa@shout.org.au](mailto:btaa@shout.org.au)

## BTAA Committee 2021

### Executive Members

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**Vice chairperson:** Janet Micallef

**Secretary:** Eliza Moloney

**Assistant Secretary:**  
Billy Williams

**Treasurer:** Pat Wynn

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Alice Parsons, Diane Dunn,  
Amanda Griffin, Di Pooley,  
Eliza Moloney, Craig Cardinal,  
Cate Baldwin

**Specialist Advisers:**  
Denis Strangman AM,  
Matthew Pitt and Susan Pitt

**Magazine/e-news Editor:**  
Philip Steel

### Public Officer:

Eliza Moloney

### Website Coordinator :

Peter Ramstadius

### WA State Coordinator:

Diana Andrew

We are always looking for more helpers and representatives, especially in regional areas and states that currently do not have representation.

# LETTER FROM THE CHAIR

## Welcome to our first magazine for 2021.

### National Brain Tumour Collaborative

This year the Brain Tumour Alliance Australia will be concentrating on proactively engaging with our national brain tumour partners to form a National Brain Tumour Collaborative. We believe there is an urgent need to address and improve survivorship of brain tumour patients, carers and families, and that all those working in the brain tumour space, including all areas of support, research and medical services, need to collaborate together to ensure a minimum and consistent level of care across the whole country. This includes ongoing care before, during, and after the diagnosis of a brain tumour not only for the social and emotional needs of those affected, but also help with such things as rehabilitation, accessing Centrelink payments and applying for the NDIS.

If we all work together, I believe we can make a significant improvement to the life of all brain tumour patients, their carers and families. A big thank you to **Craig Cardinal** who is heading this project on behalf of the BTAA team. Please take the time to read Craig's article in the magazine, as well as the other stories highlighting some of the outstanding initiatives already in operation in some centres.

### Patient Forums

Last year, all face to face Patient Information Forums in the various states were cancelled because of COVID-19. These forums were always very popular and well attended, and were missed by those affected by brain tumours, especially newly diagnosed patients and their families. This year I am delighted to announce that during **Brain Cancer Action Month** in May, forums will again be held in NSW and SA. It is intended that later in the year, forums will also be held in other states.

#### The forums being held in May 2021 include:

- **The Sydney Patient Education & Support Forum** on 20 May 2021 at the Wesley Conference Centre in central Sydney.
- **The Mark Hughes Foundation Hunter Patient Forum**, Sponsored by Mark Hughes Foundation on 28 May 2021 at the McDonald & Jones Stadium Broadmeadow, in Newcastle.
- **The Adelaide Patient Forum** on 25 May 2021 at the Adelaide University.

More information will become available shortly. Forums are free but registration is required. More information about these forums, and links to registration will be on our website at [www.btaa.org.au](http://www.btaa.org.au)

Video links from previous forums can be accessed on our website <https://btaa.org.au/resources-support/related-links>

### The BTAA Team

The BTAA team are featured in this magazine. All of our committee members are volunteers with their own unique experience of being either a brain tumour patient, carer or family member, that has led them to dedicate their efforts to helping others. As always I would like express my appreciation to these colleagues for their wonderful efforts in the many facets of the BTAA's operation.

### Fundraising

Over the last six months we have received individual funds from **David Robinson, Maria Vass, Theo Lazaris, Simon Anderson, Susan Pitt, Kenneth Enyon, Penelope Thomas, Taryn Groom, Robyn Scott and Julie Leroy**. Many thanks for these generous donations.

There was also a substantial donation in memory of the late **Bill Lazaris**. This donation will assist in the funding of the Sydney Patient Education & Support Forum over the next several years.

**Michael and Tracy Scott** continue to raise funds for the Nicola Scott Educational Grant. The money raised supports grants for nurses to attend brain tumour conferences.

Information <https://www.btaa.org.au/about/our-grants>.

**Kay and Roger Harrison** held their spectacular Christmas Light display in Canberra again. The display ran over several weeks and BTAA was a major benefactor of the funds raised. A big thank you to Kay and Roger.

We are always in need of more volunteers in all states to spread the word of the support available through BTAA. If you are interested in being involved, I would be delighted if you would contact me at [chair@btaa.org.au](mailto:chair@btaa.org.au)

I wish all, patient, carers, families, doctors, nurses, health care workers, brain tumour researcher and brain tumour support groups, a happy and healthy remainder of the year.

*Catherine Hindson  
Chair 2019-2020*



Catherine is a retired registered Nurse whose daughter was diagnosed with a Anaplastic Astrocytoma in 2010. Her daughter is now doing extremely well although Catherine recently lost her husband Bill, also a great supporter of the BTAA, from a different form of cancer. Catherine is a keen birdwatcher, gardener and volunteers a great deal of her time to the BTAA to ensure that every person with a brain tumour has all of the support and information that they need.



# Progressing a National Brain Tumour Collaborative

*Craig Cardinal*

**There is an urgent need for a national collaborative to address the current and vitally important issues impacting Australian brain tumour patients, families and carer communities.**

The Brain Tumour Alliance Australia (BTAA) has been proactively engaging national brain tumour support partners and is currently in discussions regarding opportunities and benefits of forming a national brain tumour collaborative. The aim of this collaborative is to provide a cohesive national body which will advocate for and articulate specific issues affecting brain tumour patients, families and carers (consumers) across Australia.

## The Current State

The devastating impacts experienced by Australian brain tumour consumers from date of diagnosis is well understood by the support community. However, consumers have not received due attention from the Australian government. Over recent years, Australian brain cancer medical practitioner and research communities, support foundations and philanthropists, have fought hard to draw focus to the critical need of better funding for research.

As a consequence, the Australian Government – through the Medical Research Future Fund – established the Australian Brain Cancer Mission (ABCM). The ABCM funds critical research into cures, treatments and ways to improve quality of life and survivorship. In parallel to the ABCM grant scheme, many Not For Profit (NFP) brain cancer support organisations continue to independently undertake substantial and successful fundraising activities, which seek to further fund medical research and survivorship support.

Survivorship for brain tumour consumers is a devastating journey from date of diagnosis. Consumer needs are complex and varied. The ABCM has recently provided grants to research aspects of brain cancer survivorship.

Within the various consumer support communities lies significant contemporary knowledge and understanding of consumer survivorship challenges. However, there is a lack of a national and uniform approach to brain tumour survivorship.

Funding raised by foundations go towards support services such as brain cancer care coordinators and nurses alongside services such as retreats, financial grants, music therapy and counselling services. This is an attempt to meet consumer needs that have not been met via other means.

Despite our commonality in cause and commitment, we remain more fragmented than is ideal. While it is critical to sustain the specialised focuses of individual organisations, without a collaborative to address common issues and provide

strong national advocacy, we will continue to have issues that extend and compound the suffering of our consumers.

## The Challenge

Brain tumours are very regularly causative to a substantial Acquired Brain Injury. Consumers regularly suffer significant physical, cognitive and psychosocial impairments as a consequence of disease and treatments; seizures, hemiplegia, speech impairments, cognition, depression, concentration, despair, confusion, lethargy, incontinence, mobility, employability, migraines – and so forth – are common. These impairments are most often lifelong and greatly affect sufferers and carers capacity to engage in the community. Most consumers experience devastating social and economic impacts.

Our foundations and various supports interact with thousands of consumers in a variety of different ways. Through surveys and the provision of a wide range of supports, the partner communities currently have a good understanding of the plight of consumers through their survivorship journey and the subsequent required supports.

Whilst the incidences of brain tumours are comparatively low to other tumour types and diseases, the impact of the potential resultant impairments to sufferers and families is often devastating.

## Examples

### Brain Cancer Care Nurses

We know that the quality of life and overall survivorship experiences of consumers is greatly improved when they are able to connect to support. These supports include dedicated brain cancer support coordinators/nurses – typically funded through NFP and typically only in certain regions. Foundations such as Mark Hughes Foundation, Care2Cure and others, fund critical brain cancer nurses/coordinators.

Despite this, there is no universal or national understanding of the requirements. The implementation of specialist prostate cancer nurses across Australia is an example of how government supports important programs when they have a detailed and holistic understanding of the requirements.

### Access to government services

We know that accessing NDIS changes the lives of consumers, yet the capacity required by consumers to navigate the access requirements is often greatly diminished due to nature of these impairments.

The Peace of Mind Foundation is working hard to support consumers to access NDIS. Though, without a national approach the support is very limited and unsustainable through a solely volunteer support base.

MS Australia is an example of a funded, cohesive national approach delivering a vital service of assisting their communities to access NDIS. We know that the comprehensive supports often required by our consumers cannot be met through mainstream services and require NDIS supports. Hence, access can be vital.

## Survivorship Framework and Narrative

Our patient, family and carer community are extremely vulnerable to government lacking an understanding of these significant challenges.

The Peter Mac Cancer Foundation and the Clinical Oncology Society of Australia (and the Cooperative Trials Group for Neuro-Oncology) for example, have vested heavily in cancer survivorship understanding and frameworks. Yet, there remains no national brain cancer survivorship framework that provides a unified narrative for our community.

A focused framework and narratives would allow us to advocate on national core issues and greatly assist governments and supports to understand consumer requirements.

## The aim of the Collaborative

An important role of the collaborative would be to quickly develop an understanding of the core national issues.

The collaborative would be represented by all key stakeholders (research, support foundations, NGO etc). The future funding, governance and operating model of the collaborative would need to be determined.

BTAA have engaged widely on this initiative and continue to do so. Feedback has been extremely encouraging. We will continue to work with partners to progress an inaugural meeting, which is envisaged around mid-May 2021.



**If you represent a brain tumour organisation or service and have not been contacted about this very important initiative, or would like to comment, please contact the BTAA enquiries@btaa.org.au**



## Survivorship Supported by Peace of Mind's Innovation

**Geelong based Peace of Mind Foundation has announced the arrival of Jonathan Muller, their very first 'Community Brain Cancer Support Worker', which is also a first for Australia. As Jonathan gets into his role, we asked him to introduce himself and explain his background and approach.**

"Warm wishes to all. My name is Jonathan. These past weeks I have started in the new role as a 'Brain Cancer Support Worker' for the *Peace of Mind Foundation*. The key difference is this role is not clinician focused or attached to a medical provider. The role is open and flexible and has really got my juices flowing! The flexibility of the role allows me to meet people in a more genuine capacity. To find out where they are in their brain cancer journey and begin layering support in the fashion best suited to them. I'm primarily meeting people in their home, setting a different tone from the word go.

What does support look like? Well, my visits range anywhere from 20 minutes to 2 hours, depending on the need. I'm a very experienced nurse by trade but have a broad knowledge of specialities and supports available to people. Which means I can help them to navigate the often overwhelming services that people may or may not be aware of.

I employ some 'ations' – orientation, education, navigation, information.

Alongside my experience and my wish to link people with support they need, I am genuinely interested in people and what makes them tick. What makes a person feel supported or isolated, well or unwell, engaged or at a loose end. I have done many

courses for my own development that help inform the service I can provide within the role. These include: Family Constellation Therapy, Creative Arts Therapy, Pastoral Care, Buddhist Studies and Meditation, Men's Work and University studies in the Humanities, to name a few.

Our wish here at Peace of Mind Foundation is to provide increased levels of support to people with brain cancer all over Australia. For now, I am travelling around Geelong, the Bellarine and down along the coast to the South Australia border. Within the Peace of Mind Foundation, I am supported by wonderful resources and people. I also have access to the greater community, to connect clients with what may be helpful to them in the immediate or long term. It is my wish to orientate those I meet to their current situation and facilitate their connection with themselves, their family and the broader community. To instil people and families with the courage to face the challenges. I hope to help people to make the best of the life that they have."

In his new role of 'Brain Cancer Support Worker' Jonathan has already received some wonderful feedback:

*"Hi Jonathan. We wanted to let you know how much we enjoyed your visit and appreciate the time you spent with us. Having a bigger picture of what we are facing has given my husband an injection of energy that I hadn't seen before your visit. Over the weekend he spent time on the property mowing, whipper snipping and generally enjoying time outside. Thanks heaps."*

**Peace of Mind is very grateful to Geelong Hospice Foundation for funding this position and to Apco Foundation for sponsoring all of the fuel costs of our new company vehicle.**



# Breakthrough Survivorship Diary Will Help Many

**Cassandra Bennett**

**Brains do not cope so well with sudden changes, such as an accident that may leave a patient with a brain injury, or a stroke may starve the brain of oxygen. These traumas have an immediate and devastating impact, but sometimes the slow changes can be masked, and the brain retrains itself to accommodate new challenges. In the case of slow growing tumours, the brain finds ways to work around its uninvited squatter.**

Without treatment or abatement, the tumour mass spreads like tentacles throughout the brain. These tentacles take the most efficient path through the structures of the organ, quietly embracing critical infrastructure and in turn, through the magic of neuroplasticity, the brain forges new pathways to carry out the day-to-day work, while silently contending with the intrusion.

In its brilliance, the brain finds a new way to do an old job. But the flaw in this brilliance is that while allowing the patient to live a relatively normal life, for a time, the tumour grows, undetected, unidentified, and, ultimately, uninterrupted.

Generally, medical experts cannot tell a patient how long these slow growing tumours have been in the brain before they are discovered, but in my case, it was clear, the tumour had been growing for years. By the time I was diagnosed the tumour had infiltrated several parts of my brain, with tentacles weaving around the various internal structures.

The tumour had started causing headaches that would come on in the early mornings but pass by midday, these headaches went on for months. Eventually I turned to a new GP in the hope that we could address the headaches.

As fate would have it, my new GP started her medical career as a paediatric oncologist in Ukraine, and had, unfortunately seen many brain tumours. She immediately recognised the symptoms and ordered an urgent CT scan.

And so, here we are – an extensive, stage 2 diffuse astrocytoma.

I was diagnosed on my sister's birthday, in July 2018. At the time, I was 38, married with two sons, aged 3 and 5 and I was an accountant working for a large ASX listed company, heading, a large team in a busy work environment.

Whether it be by wishful thinking or flat-out denial, it took me a little while to accept what I was up against. The mere thought of the diagnosis brought anxiety, angst, fear, and dread. So, in response, I refused to accept it.

Instead, I insisted on continuing in my corporate role despite surgery and chemotherapy. Determined to beat the diagnosis, I refused to give cancer any ground. But brain cancer has its own agenda, and eventually the brute force of the intrusion in my brain from the tumour and the chemotherapy was causing malfunctions I did not even realise were occurring.

A significant indicator of the extent of the problem was the deterioration of my memory caused by the tumour and ongoing 'silent seizures'. I would forget basic instructions, names of colleagues, and processes I had previously been an expert on.

Eventually it became clear that I was not able to function in my role, and so, begrudgingly, nine months after diagnosis, I resigned and settled into a new role of 'patient'.

When I finally took a break from working, I committed to trying to help researchers and patients in any way I could. My family and friends participated in fundraising events such as the Walk4Cancer, we ran the City2Surf in Sydney and the Point to Pinnacle in Hobart. I

designed and sold water bottles, coffee cups and t-shirts to raise money to donate to various charities, but I still felt that there was more we could do. I wanted to help people with the disease in a more direct way, but without draining resources from the research.

*'Survivorship' is a bit of a catch all term, but broadly speaking, it means to focus on the health, and wellbeing of people and their families who living with, through, and beyond cancer therapies."*

In my travels and discussions, I realised that we could offer more support to patients and their families in living with brain cancer. So, with the help of my good friend Ana, we built The Survivorship Diary. The Survivorship Diary is a tool that has been developed to help patients and their families a manage their various stages of treatment management, and care.



If I am honest, 'Survivorship' is a bit of a catch all term, but broadly speaking, it means to focus on the health, and wellbeing of people and their families who living with, through, and beyond cancer therapies. This means that brain cancer survivorship starts at diagnosis and carries on through treatments, such as surgery, radiation, and chemotherapy, into a pathway of living with the disease after treatments have been completed.

My personal experience is a little more granular than that, I found that 'survivorship' was about going about my daily life, finding new rhythms and a new focus while managing the daily impacts of the tumour and related treatments. This challenge of managing the diagnosis is more than just treatments and therapies, it is about finding a way to live a life that is directed both because of the disease, and in spite of it.

*"'survivorship' was about going about my daily life, finding new rhythms and a new focus while managing the daily impacts of the tumour and related treatments."*

The Survivorship Diary provides a short summary of the various stages of treatment, questions to ask the medical team, forms that have been designed specifically to prompt patients to collect key information at each stage of treatment, checklists for hospital packing and collection of finance and insurance details and a two-year calendar to help patients plan the various stages of treatment.

The diaries also have special pockets to keep prescriptions, referrals, repeats and imaging orders.

You can read more about the diary here [www.survivorshipdiary.com](http://www.survivorshipdiary.com)

Keeping track of this information is a meaningful, part of what it means to live with brain cancer. After I was diagnosed, I found that the time moved so quickly between diagnosis and treatment that I really did not set up an easy way to track appointments and information as it was coming in.



My hope is that this resource will help future patients face their diagnosis with a little more confidence than I had.

I have had some tremendous support while pulling this resource together. The work started about 2 years ago with my close friend Ana, who has donated her time to create and develop all the graphic design work. We have been greatly assisted by the team at Care2Cure, who have provided much needed advice and guidance on the medical detail and Peace of Mind who are managing the distribution of the diary.

I would also like to thank some key people being, my family, but mostly I would like to thank my husband Daniel. From the first utterance of the term 'brain tumour', we have been a team, and together we have moved cautiously forward in this new direction.

**The diary is free from both the website or if you want a paper copy you can contact Peace of Mind and they will post a bound copy of the diary. The first 1,000 diaries are free - after that, there may need to be a small printing fee.**

## t.s.d THE SURVIVORSHIP DIARY





# Extensive Research Supported By The Mark Hughes Foundation

The Mark Hughes Foundation (MHF) - is a Non-Profit, Health Promotion Charity that Mark (a popular ARL Newcastle Knights footballer) and his wife Kirralee began in 2014, after Mark was diagnosed with high grade brain cancer. They had no idea when they started the Foundation and set about raising funds for much needed research, the incredible amount of support they would receive from people everywhere.

To date the Foundation has raised over \$20 million and funded; a Brain Cancer Biobank, Travel Grants, multiple research projects around Australia including three Fellowships and multiple Brain Cancer Care Coordinators.

In November 2020 The Mark Hughes Foundation (MHF) added to the extensive list of world-class brain cancer research projects that it's currently supporting, awarding eight new innovation grants totalling \$1.578 million to researchers throughout Australia to undertake innovative research in the fight against brain cancer.

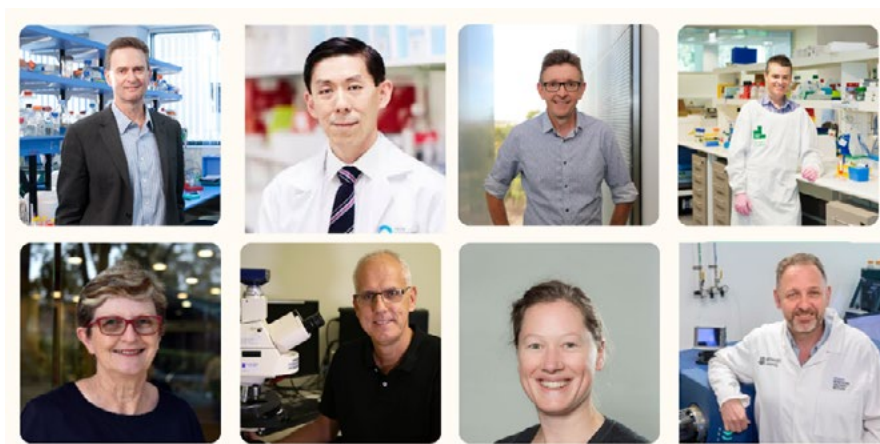
## Mark Hughes Foundation 2020 Innovation Research Grants Recipients:

**Dr Amanda Hudson** - University of Sydney - for a pilot study into early detection of disease progression in brain cancer.

**Associate Professor Paul Tooney** - University of Newcastle and HMRI - whether the brain's immune cell can be used to track treatment response in high-grade glioma.

**Dr Barbara Rolf** - University of Queensland - for new immunotherapy for brain cancer.

**Professor Hubert Hondermarck** - University of Newcastle and HMRI - for targeting ER stress-induced neurotrophism as a therapy in glioblastoma.



*Clockwise from Top Left: Professor Michael Brown , Professor Hui Gan , Associate Professor Paul Tooney, Associate Professor Joshua McCarroll , Dr Barbara Rolf , Professor Hubert Hondermarck , Dr Amanda Hudson , Professor Anthony Purcell*

**Professor Anthony Purcell** - Monash University - to investigate novel targets for paediatric brain tumour immunotherapy.

**Associate Professor Joshua McCarroll** - Children's Cancer Institute - for the development of novel peptide-decorated nanodrug carriers for the treatment of childhood brain cancer.

**Professor Michael Brown** - Central Adelaide Local Health Network - for using the immune system to target and destroy blood vessels feeding aggressive brain tumours.

**Professor Hui Gan** - Olivia Newton-John Cancer Research Institute - for therapeutic targeting of the tumour microenvironment in glioblastoma.

The Mark Hughes annual Beanie for Brain Cancer Campaign process of designing and producing one hundred and eighty thousand beanies is well into the production phase. The 2021 beanies will go on sale from June 1.

**MHF beanies** can be purchased from June 1 via the MHF website [Beanie for Brain Cancer](#) - [Buy a Beanie here](#) and in-store at participating IGA & Lowes Australia retail stores.





# BRAIN CANCER ACTION MONTH

## Time to Kick the Survivorship Goal

Brain tumour patients, their carers, and families have a unique set of needs, before during and after their treatment for a brain tumour. While most will not carry obvious signs they have been affected by a tumour, many will suffer from ongoing issues related directly to the damage in their brains, so “Survivorship”, is paramount.

As Cassandra Bennet says in her article in this issue,

“ ‘Survivorship’ is a bit of a catch all term, but broadly speaking, it means to focus on the health, and wellbeing of people and their families who living with, through, and beyond cancer therapies. This means that brain cancer Survivorship starts at diagnosis and carries on through treatments, such as surgery, radiation, and chemotherapy, into a pathway of living with the disease after treatments have been completed.”

Unfortunately the access to care and services to improve brain tumour Survivorship is inconsistent across Australia. In some areas, patients, carers and their families, are supported by excellent services, while in others the level of care is almost non-existent. When good services exist, it is often the result of active and dedicated community groups, that work to raise funds and build these, or individual hospitals and their staff who try to address patient needs.

It is time for all; patients, carers, families, brain tumour organisations, medical professionals and government, to work together to build a universal framework for quality brain tumour Survivorship across Australia. In this issue we have included some of the work of individuals and organisations working for the Survivorship goal.

## Griffith Uni Study Targets Facebook aHealth Intervention for Support

**An m-health intervention to support family members after brain cancer diagnosis: information, peer support and facilitating gratitude using Facebook (FACESup)(GU Ethics Ref. No: 2020/616) is being undertaken by Griffith University in Queensland. Supporting a person with brain cancer is difficult and influences our ability to access support and information.**

The innovative study will explore if using a Mobile-health intervention improves the access of healthcare information and support for family care-givers of persons with brain cancer by developing and evaluating the effectiveness of an online intervention, which provides information, peer support and facilitates gratitude using Facebook.

Participants are currently being sort to take part in this study to evaluate the effectiveness of m-health as a health practice presented using mobile or personal digital devices. Participation in the study will involve either being in the intervention group FACESup and staying connected via Facebook for a ten-week delivery of online information and peer support.

The intervention group will complete online surveys at the start, week 10 and week 18, and a telephone interview at ten weeks. The total time will be over 18 weeks.

If you would like to participate in this study, we ask that you read the information sheet at the start of the online survey, and complete the online survey. Using the link below.

<https://prodsurvey.rcs.griffith.edu.au/prodls200/index.php/433753?lang=en>

**If you have any questions about this project please contact Dr Elisabeth Coyne by telephone: 0403021699 or email: [e.coyne@griffith.edu.au](mailto:e.coyne@griffith.edu.au)**





## “We’re all in the same boat”: Cancer Council’s Telephone Support Group for people living with a brain tumour

**Cancer Council NSW runs a telephone support group for people who are living with a brain tumour. It is accessible to people located all over Australia. The aim of the group is to provide emotional support to the participants, helping them to feel less isolated. It also provides an opportunity to share information and openly discuss the concerns and challenges of living with a brain tumour.**

There is no cost to join and members can participate as often as they wish around medical appointments and other commitments, with many participating from the comfort of their own couch at home. These groups are a safe and confidential meeting space for those who might not have other people to connect with in their community. Groups are facilitated by trained health professionals.

Andrew has participated in the telephone group since 2017. He finds that “hearing what other people are going through and what works for them gives me support with what I am going through...I find strength from the others in the group. Thank you to Cancer Council for this service.”

Even with a wide diversity of location or personal situation, members say that talking with others who have also been diagnosed with a brain tumour gives them a lot in common and lots to talk about.

Leonie, a Wiradjuri woman and artist, has been in the group since 2015. “I am proud to do the Welcome To Country at each group. the group is very helpful as it means we can talk about our tumours with everybody & share with each other. Talking together gives lots of different suggestions in how to deal with what we experience.”

The **Brain Tumour Telephone Support Group** meets for an hour-long phone conversation on the first and third Monday of every month from 1.30pm to 2.30pm (Eastern Standard Time). Participants are connected into a conference call.

The needs of carers are also recognised with the opportunity to talk to others in a caring role in the **Carer’s Telephone Support Group**. Though not a tumour specific group, carers can support one another through their shared experience, and feel less isolated.

**If you would like to know more about Cancer Council’s Brain Tumour and Carers Telephone Support Group please call the team toll-free on: 1300 755 632, enquire through the Cancer Council Information and Support Line: 13 11 20, or email us: [tsg@nswcc.org.au](mailto:tsg@nswcc.org.au)**





# The Multi-Arm GlioblastoMa Australasia (MAGMA) Trial



**Glioblastoma (Grade IV glioma, or GBM) is the most common and aggressive primary brain cancer, and kills more than 1,500 Australians each year. Unfortunately, no significant improvements in treatment for glioblastoma have occurred for many years, in part because trials in this rare cancer are difficult.**

The Multi-Arm GlioblastoMa Australasia (MAGMA) study has been created to address this unmet need and aims to improve glioblastoma treatment. It is currently testing whether starting chemotherapy as early as possible after surgery or whether continuing chemotherapy for as long as it is effective and tolerable improves the survival of people with glioblastoma compared to the current standard treatment. These two study questions are easy to run at any treating site and can be immediately added into clinical practice if found to be better than current standard treatment.

The MAGMA trial is an Australian investigator-led trial for patients with newly diagnosed glioblastoma. MAGMA recruited its first participant in September 2020. Despite opening in the middle of the COVID pandemic, MAGMA has already enrolled 52 participants and opened at 13 sites throughout Australia in its first six months. Currently, MAGMA plans to expand up to 30 sites and 300 participants with the potential to grow further.

Extending chemotherapy treatment before and after current standard treatment are just the first two questions in the study. The MAGMA study is designed to rapidly begin studying new 'test' treatments for glioblastoma across participating sites without setting up a whole new trial. This design allows more people with glioblastoma to participate in clinical trials testing new treatment ideas faster.

Future experimental arms may involve novel treatments, repurposing of existing medicines, novel sequences of drugs and other treatments, novel ways to delivering existing treatments, or biomarker directed therapies (trying to work out which treatments work in some people and not others). Extra arms will be added as funding and collaboration opportunities permit.

Another innovation of MAGMA to try to make the trial as effective as possible is to share credit for the work more evenly amongst all the research staff, nurses, and doctors at hospitals across the country. MAGMA is run through the Cooperative Trials Group for Neuro-Oncology, (COGNO) which is a collaborative trials group in Australia addressing clinical trials questions in people with brain cancers. MAGMA is coordinated by the NHMRC Clinical Trials Centre and is supported by the Australian Government Medical Research Future Fund (MRFF) and co-funded by Carrie's Beanies 4 Brain Cancer Foundation and Mark Hughes Foundation as part of the Australian Brain Cancer Mission (project number MRF1170193). Funding is being sought to open MAGMA in New Zealand.

**If you would like further information about the MAGMA trial, follow @MAGMATrial on Twitter, the trial is registered on the Australian New Zealand Clinical Trials Registry under ACTRN12620000048987 and speak to your treating clinician.**



**TO LEARN MORE ABOUT  
MAGMA WATCH A  
SHORT VIDEO HERE**

<https://youtu.be/XiFgAzvomTo>

# MEET THE BTAA TEAM 2021

The Brain Tumour Alliance Australia is run by a dedicated and enthusiastic team of volunteers. Each one has been touched in some way by a brain tumour, as a patient, as a carer, or as a family member. The BTAA seeks to: Support, Inform, Represent and Connect members of the brain tumour community throughout Australia.



**Catherine Hindson**  
CHAIR AND HELPLINE

Catherine joined BTAA after her daughter Renee was diagnosed with an anaplastic astrocytoma in 2010. Catherine's passion is to make sure every person diagnosed with a brain tumour is able to access information and support. Catherine took early retirement in 2006 to become a full time carer to her late husband Bill, who passed away with multiple myeloma in 2017. She lives in Canberra where her two daughters, and her three grandchildren are nearby. Renee is now 45 and still doing well.



**Janet Micallef**  
VICE-CHAIR AND HELPLINE

Janet is a Melbourne based patient and co-founder of Grey Matters Brain Tumour Support Group. Her Brain Tumour Journey started in 1984 with a Meningioma and her last operation was in 2018. Retired from the Commonwealth Public Service after 30 years and now Janet is enjoying giving back to others through support and assistance on their BT Journey.



**Pat Wynn**  
TREASURER, CANBERRA  
SUPPORT GROUP  
COORDINATOR

Pat's husband Pete has had three craniotomies, the first in 1988, the second in 2004 and the most recent in 2015. He has had a low grade Oligodendroglioma, ranging from Grade 2 (the most recent) to Grade 3-4 for the previous two. Pat had never previously sought support until after the 2015 recurrence, when the affects of anti-seizure medication and tumours started to have a more significant impact on their lives. Being able to connect with people going through similar situations has been beneficial in helping them deal with their 'new normal' life.



**BRAIN TUMOUR  
ALLIANCE AUSTRALIA** Inc.  
1800 857 221



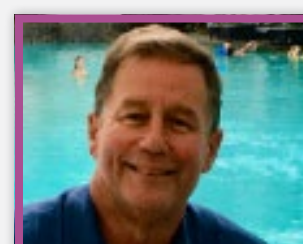
**Eliza Moloney**  
SECRETARY AND  
PUBLIC OFFICER

In 2017 Eliza was diagnosed with a rare brain tumour, a craniopharyngioma. By the time she had surgery it had grown to a large size; although she had a total resection, she was left with a non-functioning pituitary gland and has had a long process to full hormone replacement. Eliza is a passionate advocate and has learnt a lot about systemic and self-advocacy in the health system. She is now a registered consumer representative and is also passionate about achieving an affordable, accessible, inclusive and holistic healthcare system.



**Billy Williams**  
ASSISTANT SECRETARY  
AND HELPLINE  
COORDINATOR

Billy's wife Lynette passed away from a glioblastoma multiforme in 2017. It was the realisation of the impact the disease had on his family over a two year period that has led him to serve on the BTAA's committee. He has received strong support through the monthly meetings held in Canberra. He has three adult children and two grandchildren. Billy is a retired diplomat who served overseas in Africa and South East Asia.



**Philip Steel**  
EDITOR MAGAZINE & ENEWS

Philip was diagnosed with a Right Parietal Meningioma in 2011 and had a successful craniotomy shortly thereafter. Following a few months rest and recuperation Philip was able to return to his work as a high school principal, despite some adverse effects from the tumour and surgery.

Philip would especially like to see world-class and seamless brain tumour care coordination become the rule in all Australian brain tumour hospitals.





**Alice Parsons**  
COMMITTEE MEMBER,  
SYDNEY SUPPORT GROUP  
COORDINATOR

Alice's 31 year-old son, Harry has an Anaplastic Astrocytoma, which was diagnosed in June 2015. She is his primary carer. He has had two craniotomies, a major stroke and a Pulmonary Embolism. Cheerfully, he suffers few deficits today and his rehabilitation has been excellent. Alice lends her energy to helping others in a similar predicament, in the manner in which she has been helped by BTAA. Alice is married with three other adult children, two dogs and an enduring love of language.



**Di Pooley**  
COMMITTEE MEMBER,  
SYDNEY SUPPORT GROUP  
COORDINATOR, AUSTRALIAN  
MENINGIOMA SUPPORT GROUP

Di entered the Brain tumour world 34 years ago, losing a young, very close loved one to this insidious disease. Then in 2015, she became unwell and was eventually diagnosed with a large 8cm meningioma on my brain, which was successfully removed 24 hours after it was first identified. Tragically her older sister was admitted to the same hospital, 2 days after her surgery, and was diagnosed with multiple metastatic brain tumours. She has since passed away. Di is retired with a background in health care and planning, and manages the online Australian Meningioma Support Group which has 412 members and is growing daily. She is also part of the Sydney Peer-to-Peer Support Group Leadership Team. This group is very welcoming, proactive, informative and for me, it is a place to provide a voice for the many primary benign brain tumour survivors.



**Amanda Griffin**  
COMMITTEE MEMBER,  
TWITTER AND FACEBOOK  
COORDINATOR

Amanda's daughter Erin was diagnosed with DIPG in February 2012 at the age of 12. Erin fought brain cancer for two and a half years during which time she became an international advocate for kids with cancer. Erin passed away aged 14 on 1st September 2014. Throughout Erin's cancer journey, we became involved with numerous organisations in Australia including Cure Brain Cancer Foundation, CCIA, The Cure Starts Now and the Coalition Against Childhood Cancer.

After taking some much-needed time-out to grieve for her daughter, she now feels the time is right for her to become actively involved in the brain cancer community within Australia. I believe BTAA offers an incredibly valuable resource to brain tumour patients and their families.



**Peter Ramstadius**  
WEBSITE COORDINATOR  
AND HELPLINE

Peter is a semi-retired civil engineer from Coffs Harbour. He has enjoyed a varied career specialising in construction project management for both government and the private sector, but more recently in a self-employed role working in the mining industry. Peter became involved in the brain tumour community when his wife, Jenelle developed a GBM and passed away in 2017 after a 20-month battle. Jenelle had had an unrelated meningioma removed a few years earlier. Peter has four adult children and is keen to utilise the knowledge gained through his wife's journey to assist others.



**Diane Dunn**  
COMMITTEE MEMBER,  
FUNDRAISING  
COORDINATOR

In November 2016 Diane received a diagnosis of Grade 2 oligodendroglioma in her right parietal lobe and was advised it was inoperable. In common with most brain tumour patients, she was completely blindsided by this unexpected diagnosis. Prior to this, she was a very fit 54-year-old - vegetarian since 18, a non-smoker, and a non-drinker. As a result of her diagnosis she lost her small business and, as is often the case for self-employed people, she didn't have leave entitlements to fall back on. Diane has a burning desire to bring awareness of brain cancer to the forefront of cancer discussion in this country.



**Cate Baldwin**  
COMMITTEE MEMBER,  
FUNDRAISING  
COORDINATOR

In mid-2018 Cate was diagnosed with an aggressive brain tumour - glioblastoma multiforme (GBM). Following surgery, she had 6 weeks of radiation and concurrent chemotherapy, and a further 6 months of chemo followed. Despite this, her condition is treatable but not beatable and she lives with the expectation that her cancer will recur. The treatment she had has been the standard of care since 2005. That's 15 years since there has been a major breakthrough in treatment protocols for this type of brain cancer. While brain tumour patients and their families wait for effective treatments, support is vital, which is why she volunteers with the BTAA.



**Pam Hubner**  
COMMITTEE MEMBER

Pam's daughter was diagnosed with a brain tumour in 2011, two months before her 37th birthday. After being told her daughter's tumour was inoperable, it was through the information received from BTAA that Pam learnt the importance of asking questions and the seeking of a second opinion. At the age of 44 after an almost 8-year journey, Angie passed away on 27th October 2018 leaving behind a husband and three young children. Pam lives in Queensland and continues, when she can, to assist BTAA with their endeavours for ongoing support for Brain Tumour/Cancer patients and their families



**Craig Cardinal**  
COMMITTEE MEMBER,  
NATIONAL ENGAGEMENT  
AND STRATEGY  
COORDINATOR

Craig's wife, Berlanda, was diagnosed with high-grade brain cancer (Anaplastic Oligodendroglioma) in late 2015. Despite having the best of specialist care, Berlanda has suffered a range of setbacks and impairments from disease and treatments. Craig left his employment 3 years ago to provide full-time care for Berlanda. Craig is passionate about ensuring that the significant impacts from the disease are understood across governments and communities. He also volunteers with the Peace of Mind Foundation. His Involvement with the Foundation is focused on connecting patients and families to critical government supports such as the NDIS. Craig served in two arms of the Australian Defence Force and had a long career in the Commonwealth public sector. He has consulted to governments and industry.

UPCOMING  
EVENT

# SYDNEY PATIENT EDUCATION & SUPPORT FORUM

for brain tumour patients Hosted by NSW  
Neuro-Oncology Group (NNOG) and  
Brain Tumour Alliance Australia (BTAA)

NSWOG  
NSW oncology groups



Brain  
Cancer  
Action

Ideas, Research, Hope.

WHEN

20 MAY 2021  
9.00AM – 3.00PM

WHERE

WESLEY CONFERENCE CENTRE,  
220 Pitt Street, Sydney



BRAIN TUMOUR  
ALLIANCE AUSTRALIA Inc.  
1800 857 221

## EVENT DETAILS

### MORNING SESSION DR BEN KONG (CHAIR)

9:00 – 9:30 Registration (tea/coffee)

9:30 – 9:45 Introduction and welcome –  
*Dr Ben Kong, Catherine Hindson*

#### SESSION 1

9:45 – 10:05 Surgery: when is the best time to resect, benign vs  
aggressive lesions, what to expect – *Dr Jonathon Parkinson*

10:05 – 10:25 Radiation: basics of radiation treatment, newer  
imaging modalities that you may undergo as a patient  
– *Prof Michael Back*

10:25 – 10:45 Medical Oncology: overview of systemic therapy plus  
brief on COGNO trials – *Dr Hao-Wen Sim*

10:45 – 11:05 Morning tea Session 2 – Supportive Care  
– *A/Prof Elizabeth Hovey (Chair)*

11:05 – 12:30 Panel discussion and questions  
*Dr Jonathon Parkinson, Prof Michael Back, Dr Hao-Wen Sim,  
Marina Kastelan*

12:30 – 13:15 Lunch

### AFTERNOON SESSION KAYE DUFFY OAM (CHAIR)

#### SESSION 2

13:15 – 13:20  
Introduction – *Kaye Duffy*

13:20 – 13:50  
Symptoms to expect with brain cancer – *Marina Kastelan*

13:50 – 14:30  
Rehabilitation – *Prof Andrew Cole*

14:30 – 14:50  
Services available – *Cancer Council NSW*

14:50 – 15:00  
Wrapup

## HOW TO REGISTER

VISIT [WWW.BTAA.ORG.AU/EVENTS](http://WWW.BTAA.ORG.AU/EVENTS) OR PHONE 1800 857 221  
PARKING NEARBY CAN BE BOOKED VIA: HILTON SYDNEY CAR PARK

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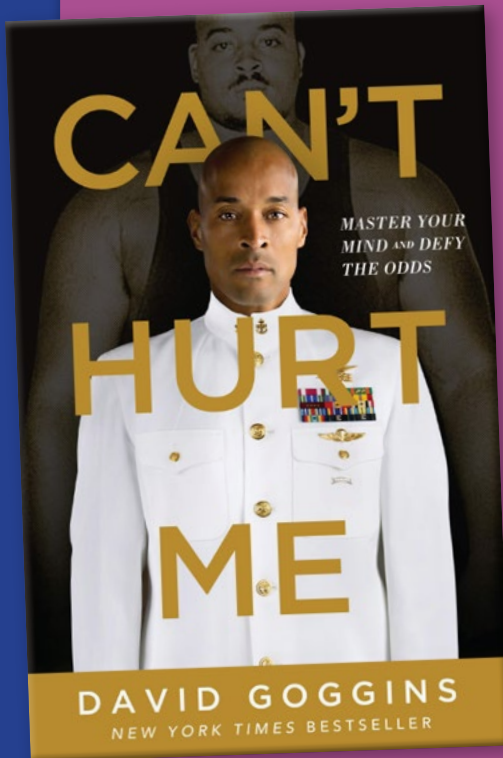


Cancer Institute NSW



## NATHAN'S BOOK REVIEW

# CAN'T HURT ME by David Goggins



I tried something new for this book, as I was on a huge drive to QLD and back recently, so I used Audible for this book and another. The awesomeness about this book via audible is that the book is read by David's ghost writer Adam, and the style is totally different to a usual audio book. This reading is book/interview/podcast and a heap of extra context and backstory, that is usually not heard or read by the reader. At the end of each chapter readers are drawn along a journey of self-improvement and reflection through small challenges that extend upon the theme of each chapter.

Before I get into this review, a bit of a warning or caveats. This is a book maybe, not for everyone. Firstly, there is a language warning, and secondly this guy and his life story is just hyper positive, it may wear you out just reading it.

For me when I read a book, I am looking for the concepts, and the main takeaways. Not seeking offence from a few words here or there that I may not like to use or hear used. But in this case I won't make an excuse because this book is an open book into the life and mind of an incredible human. Goggins tells an amazingly gritty story detailing surviving horrific abuse at the hands of his father through to being one of the fittest men in the United States if not the world. To clarify, the first few chapters are a tough read. And through the early parts of the book the reader gains a view of a person at the bottom of the barrel, in fact perhaps even trapped under the barrel itself. At the least a future statistic, or a guy pre-programmed to fail.

As the book moves forward a strength of spirit and drive emerges as Goggins realises he has a depth of strength he never envisaged. As the middle few chapters detail, our physical limitations can be self-imposed walls to achievement of goals and dreams. Goggins realises that his power rests within his mind,

both conscious and sub-conscious. His introduction of the concept of an 'Accountability Mirror' (yep just a mirror in his bathroom) is a huge change to his life. This is a space where you become accountable to yourself alone. This is a gift (among many) he gives to the reader. You will never look at another reflection of yourself in the same way again!

As the book progresses Goggins takes you on his life journey from a depth few of us could understand to completing the US Air Force para-rescueman training, passing the Army Ranger course, and becoming a US Navy Seal. He is the only person to have ever completed all three armed services Special Forces training programs. His Seal course had to be done three times as you will read.

During these achievements he found Ultra marathons and triathlons and eventually to becoming the world record holder in another discipline. You can read about that, I won't spoil it for you.

On reflection the three big concepts of the book, are that you can make you, physical barriers are there to be worked with and through, and mental attitude can be changed and is the real key to your future. Without a therapist in sight Goggins looks deep into his soul and mind and works himself out, breaking barriers at all corners. He acknowledges he isn't perfect. But who is?

I thoroughly enjoyed this book and is my current recommended reading to anyone I bump into!! I defy anyone to read it and not get something from it.

Just search for *Can't Hurt Me* on [www.audible.com.au](http://www.audible.com.au)

Stay awesome and happy reading,

**Nathan Draper**



### Book Reviewer: Nathan Draper

Nathan linked up with his local BTAA group in Canberra after receiving diagnosis of GBM grade IV in October of 2019, at the age of 49. His tumour has been debulked, Radiated and Chemo'd. He is an Aeronautical Engineer in the Air Force and is married to Christine with two boys (19 and 15) as well as getting to the gym, riding his bikes, and reading stuff to keep him going, which he loves to share.

You can check his blog out here: [www.bu11itt.wordpress.com](http://www.bu11itt.wordpress.com)

# 13<sup>th</sup> COGNO ANNUAL SCIENTIFIC MEETING

## *Brain Cancer 2021: Concepts to Cure*

Sunday 24<sup>th</sup> - Tuesday 26<sup>th</sup> October 2021

MELBOURNE, AUSTRALIA

A hybrid event, with the option to attend virtually

### INTERNATIONAL SPEAKERS



**PROFESSOR NINO CHIOCCA**

MD PhD FAANS



**PROFESSOR GELAREH ZADEH**

MD PhD FRCS FAANS

Stay posted for further updates, or email [cognoasm@ctc.usyd.edu.au](mailto:cognoasm@ctc.usyd.edu.au) to join our mailing list.



**COGNO**  
COOPERATIVE TRIALS GROUP  
FOR NEURO-ONCOLOGY



## SPREAD THE WORD!

Please LIKE, ADD, SHARE, COMMENT and SPREAD the word via our Twitter, Facebook and LinkedIn accounts! This not only helps our voice to be heard but also gives you a chance to reach out, interact and communicate with BTAA and the wider brain tumour community!

**1800 857 221**  
**www.btaa.org.au**



Brain Tumour Alliance Australia



@BrainTumourAA



Search 'BTAA' on YouTube



**BRAIN TUMOUR**  
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Printed by **Mavericks Printers**

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