



# National Advocacy Service

Client Information Booklet



# Welcome

on behalf of the National Advocacy Service team

From the staff and volunteers of the National Advocacy Service (NAS) please accept the warmest of welcomes.

Through our personal and professional experience, we realise that you are going through a complex and vulnerable time with no certain outcome. We embrace and operate under the understanding that we will be working with you wherever you currently find yourself in your Brain Cancer Survivorship.

We use the term Survivorship in recognition that every day from diagnosis is an achievement and that we are committed to supporting you in whatever way we can to get the help you need, here and now.

This booklet is our way of providing you with information about what services and support you can expect from us.

We look forward to getting to know you and providing you with the support, courage and community that meets your needs here and now.

## Fiona Hassmann

Manager, National Advocacy Service



# Meet the Team

## Fiona Hassmann

Manager, National Advocacy Service

[fiona@peaceofmindfoundation.org.au](mailto:fiona@peaceofmindfoundation.org.au)

Fiona's personal experience with Brain Cancer, and the struggles associated with finding help and guidance, led her to National Advocacy Service.

Fiona is passionate about helping patients, carers, and families, empowering them with guidance and encouragement. Recognising that not all people are able to find a voice for themselves when lost in the heartache of this disease, she is ready to step up and assist in any way that she can.

Her passion is to ensure that all families in the brain cancer community are provided with the highest level of support available to them. When not working, Fiona enjoys being at home with her family, cooking, baking and gardening.



## Helen Kington

Advocate

[helen@peaceofmindfoundation.org.au](mailto:helen@peaceofmindfoundation.org.au)

Helen is passionate about helping families in the brain cancer community access the support they need. She strongly believes in collaborating with healthcare teams to provide the high-quality support that every person deserves.

Helen's professional experience consists of over 25 years in the nursing industry as a trained endorsed enrolled nurse, providing all levels of care across disability, dementia, palliative, mental health, and brain cancer patient care.

She understands that support needs to focus not only on physical needs, but mental needs too, focusing on a holistic approach, listening to concerns, and developing an individualised approach to every person.



## Mary Sutton

Advocate

[mary@peaceofmindfoundation.org.au](mailto:mary@peaceofmindfoundation.org.au)

Mary has always had a passion to help people in the community. After losing a loved one, she created the first 'Crohn's and Colitis Support Group' on the Gold Coast, and believes there is great importance in being able to talk with others living with the same disease. "Supporting each other, sharing experiences and learning from each other can provide significant mental health benefits and a sense of 'you are not alone' in your journey".

Before coming to the National Advocacy Service, Mary worked in state government for over 23 years across a variety of areas and understands how to best assist patients, carers, and families in accessing the supports they need.

Outside of work, she is a lover of the great outdoors and enjoys camping, chasing waterfalls and spending time at the beach with her fur babies and family.





# Introduction

**VISION:** Every family in Australia impacted by brain cancer will get the support they need.

**MISSION:** To give support, courage and community to brain cancer patients and their carers, family and loved ones.

**A DIFFERENT ANGLE:** We understand the stress, anxiety and journey that brain cancer patients, their families and loved ones go through. To help improve quality of life and survivorship our services focus on providing supportive care HERE and NOW for patients and their families across four key areas:

- **Counselling & Wellbeing**
- **Financial Assistance**
- **Resources and Advocacy**
- **Retreats & Community Events**

Whilst we are not an organisation that undertakes research in brain cancer, we fully support all organisation and funds raised in the mission to find a cure. It is our hope that by tackling brain cancer from both angles, we can achieve the greatest support for everyone who comes into touch with the diagnosis.



# Why we got started

---

Having lived through the emotional and pragmatic challenges of a family member with brain cancer, CEO Bec Mallett and her brother Clint founded the organisation to provide the much needed and often difficult to find support and care for patients and family.

The organisation was created in honour of Clint's wife and Bec's sister-in-law, Caroline Maree Matthews.

The Peace of Mind Foundation (POMF) in partnership with the Cure Brain Cancer Foundation created the National Advocacy Service (NAS) as there was no service providing the essential support and advocacy to effectively connect the brain cancer community to government and community support.

The overarching scope of the NAS is to enhance the experience and optimize support for those impacted by brain cancer.

The NAS delivers support and advocacy to those who are unable or struggle to self-advocate, and helps them connect to critical community and government services. We provide these supports to people who have a primary diagnosis of brain cancer and those that support them.

The NAS also advocates more broadly on issues related to Brain Cancer Survivorship and its impacts on patients, their loved ones, and families who support them.

# What we do

## **We provide general advice, guidance and support to connect to government-funded services and support**

NDIS, Disability Support Pension, Carer Pension and Allowance, My Aged Care (State or Federal government services).

## **We support initial review processes following a rejection of access to these services**

Guidance through review processes, connection with funded advocacy services.

## **We assist in identifying and connecting consumers to not for profit supports**

Carer Gateway, financial counseling, and legal aid.

## **We assist to connect to the community and non-government funded supports**

Support groups, counselling, POMF brain cancer retreats, and community events.

## **We formally advocate on behalf of brain cancer consumers on survivorship issues**

Respond to government issues that affect consumers, support survivorship research, collaborate across partner foundations.



# What we don't do

## **We are not a crisis or emergency service**

We engage with compassion and empathy and we connect people with services that can provide this support as required.

## **We are not a counselling service**

We engage with compassion and empathy and we connect people with services that provide this service as required.

## **We do not provide formal legal representation**

We provide options for people to secure this representation should they so choose.

## **We do not provide formal NDIS support services**

We do advocate with and on behalf of clients with the providers of these services.

## **We do not provide clinical, medical or treatment advice**

We do advocate with and on behalf of clients with the providers of these services.

# Survivorship

The phrase “cancer survivorship” was created to describe this broad experience on the cancer continuum – living with, through, and beyond a cancer diagnosis. *Source: The NCCS Definition of a “Cancer Survivor” (canceradvocacy.org)*

The NAS embraces and operates under the understanding that we are working with and for our clients wherever they are in their brain cancer challenge. We use the term Survivorship in recognition that every day from diagnosis on is an achievement and that we are supporting people through a complex and vulnerable time with no certain outcomes.

We celebrate your Survivorship every day and advocate for your access to the services and support that will optimise your experience here and now.

For the NAS to be effective, we must assist our clients to make timely connections with services that can, and do, provide support to maintain or re-instate these rights.

## What is Advocacy?

**The word advocacy comes from Latin and means ‘to be called to stand beside’**

The NAS undertakes two primary forms of advocacy, Individual Advocacy and Pro-Active Advocacy. In our Individual Advocacy, we also support you to develop Self Advocacy skills, where appropriate.

In undertaking Individual Advocacy with you, we are informed by the following definitions:

Advocacy involves standing beside someone and supporting them. Advocacy seeks a satisfactory outcome for a person, so as to enhance their rights and dignity. It has a connotation of change, challenging what is unfair, unjust and wrong. *Source: What is advocacy | Adacas*

A focused form of communication or activity promoting our clients and their supporters' rights to access the support they need when they need it. *POMF and NAS discussions*

A cornerstone of our advocacy approach is to work 'with' you to ensure you are aware of your options and give timely advice and support on how and when to best access those options.

Our advice & support is only ever general in nature and not prescriptive.



# Self Advocacy

One of our primary aims in advocating for you is to promote your capacity to retain as much control over your lives as possible, and in so doing achieve the outcomes you want. This provides us as advocates with the challenge to discern when it is appropriate to advocate for you and when it is appropriate for you to advocate for yourself (Self Advocacy).

**The NAS can assist with helping you if you want to develop your self-advocacy skills by providing information and support.**

As with access to services, the choice between actively advocating for you and promoting your capacity to self-advocate is entirely dependent on the circumstances as they arise. Almost always this will be driven by you in terms of your capacity at the time and the complexity or novelty of the task at hand.

**Whatever your choice our overriding aim is to ensure you feel supported and know that we are there for and with you.**

## How our Advocacy Approach is Informed

The NAS derives authentic advocacy perspectives from people who have lived experiences of brain cancer, families, workers and others – all of these influence and guide our approach to advocacy. Perspectives and experiences are derived from:

- **The lived experience of clients of the NAS and POMF programs, including family and carers**
- **The knowledge, experience and views of the NAS and POMF staff, and volunteers.**
- **Knowledge and expertise of sector partners, peak bodies and advocacy organisation.**
- **Views expressed by members of the brain cancer community.**
- **The NAS actively seeks out feedback from our clients via service exit and annual Surveys to improve our service and inform our advocacy practice.**

# Feedback

When our service concludes we will send you a short, anonymous, feedback questionnaire. We do this to build our capacity to meet our clients' needs, improve our service where we can and as an evidence base to seek further funding for the service. We will also send out annual surveys asking broader questions to inform our proactive advocacy on behalf of the brain cancer community.

You can also provide us with ongoing feedback anytime via email at [nas@peaceofmindfoundation.org.au](mailto:nas@peaceofmindfoundation.org.au).





>> [www.peaceofmindfoundation.org.au](http://www.peaceofmindfoundation.org.au)

>> [www.curebraincancer.org.au](http://www.curebraincancer.org.au)

A graphic of a human brain with colorful circuitry lines (blue, green, yellow, red) overlaid on it, representing neural pathways.

National Advocacy Service