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NDIS Abandons Brain Cancer Sufferers

National brain cancer support foundation calls for urgent action

Australians diagnosed with brain cancer are now facing a harsh rejection for disability supports due to recent changes to the NDIS.

Brain cancer kills approximately 1800 Australians each year with more children dying from the disease than any other disease and more people under 40 succumbing to brain cancer than any other cancer.

Most brain cancer patients will suffer a range of significant permanent disabilities because of the disease and treatments.

Until June last year, the NDIS supported brain cancer patients that met the criteria through funded disability supports. Brain cancer patients were previously supported for their disabilities through the NDIS and in parallel, received palliative care needs through state based mainstream systems.

Without notice to this extremely vulnerable community, the NDIA began rejecting brain cancer patients to access the NDIS and stated that they are palliative and to go to palliative care for supports in the state-based systems. NDIA are currently rejecting brain cancer patients despite acknowledging their significant and permanent disabilities and that palliative care does not provide the level of disability supports required.

The National Advocacy Service (NAS), managed and operated by Peace of Mind Foundation and funded through Cure Brain Cancer Foundation, are seeing firsthand the immediate and devastating affect this change in assessment for brain cancer has on sufferers and families.

The NAS provides direct advocacy and support to around 800 patients and families across Australia.

Founder and CEO of Peace of Mind Foundation Rebecca Mallett said it is time for the Government to intervene and ensure that people continue to access the support they desperately need.

“This unannounced change in access assessment for brain cancer patients is incredibly unfair to a very vulnerable community. We have worked extremely hard to support families connect with services as we are acutely aware of the devastation to patients and families from disease and treatments. This undeclared change in policy by NDIS simply cannot continue and we need the NDIS to revert to providing the disability supports to these patients and families that they are legally entitled,” she says.

According to Fiona Hassmann, Manager of National Advocacy Service, “Our patients are faced with a highly degenerative disability with shocking impacts to their physical, cognitive, and behavioural wellbeing, leaving them unable to work or drive and, in a majority of cases, care for themselves independently,” she says.

“In June 2023, government agency NDIA, without any consultation or transparency, changed the decision-making process, rejecting almost every claim lodged on behalf of brain cancer sufferers which is having a desperate impact on our community.”

In partnership with the Australian Brain Tumour Collaborative, Peace of Mind Foundation has spent months battling the sudden rejection of NDIS applications. Despite initial positive support from Minister Shorten at which NDIA were instructed to come up with a solution, claims are continuing to be rejected and families continue to struggle.

“NDIA have changed the goal posts and now refuse to acknowledge the dire impact of this change. Patients are now faced with extreme difficulty in maintaining any quality of life and told they must turn to palliative care as their only option,” according to Hassmann.

“Approximately 75 per cent of the original high need cases that required urgent attention and were presented to the Ministers office and the NDIA in June 2023, have now passed away. They were rejected from the scheme that once supported this community, and they died without the supports they and their families desperately needed and entitled.”

Cancer patients in general around Australia are feeling the impacts from recent changes in NDIS policy. Many will need to go through the lengthy and challenging path of having their cases assessed at the Administrative Appeals Tribunal or other legal processes with some applicants already on this path.

“There remains a broader and equally concerning future for the brain cancer community. The changes to the NDIS that is currently being negotiated across commonwealth and state departments could see brain cancer patients fall into a bureaucratic hole and not receive the required supports. By this time next year, unless this change in policy reverts, there will be a large number of disabled brain cancer patients that will pass away without the disability supports they desperately need.”

The Australian Brain Tumour Collaborative and Peace of Mind Foundation are continually engaging government and seeking immediate change.

Peace of Mind Foundation

Peace of Mind Foundation is Australia’s largest brain cancer support charity, supporting over 800 families every year. Its National Advocacy Service, funded by Cure Brain Cancer Foundation supports brain cancer patients from diagnosis to bereavement, assisting many with applying to NDIS to fund vital supports. Peace of Mind Foundation provides supportive care programs and services across Australia for families impacted by brain cancer.

Visit peaceofmindfoundation.org.au

INTERVIEW OPPORTUNITY AND PATIENT STORIES

Peace of Mind Foundation's National Advocacy Service is actively supporting many families nationally facing NDIS rejection and can coordinate interviews with patients and their loved ones.

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