

**Submission  
No 19**

**A FRAMEWORK FOR PERFORMANCE REPORTING AND DRIVING  
WELLBEING OUTCOMES IN NSW**

**Organisation:** Grief Australia

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# Submission to the Inquiry: A framework for performance reporting and driving wellbeing outcomes in NSW

Grief Australia welcomes the opportunity to respond to the current Inquiry by the Public Accounts Committee, which is reviewing a framework for performance reporting and driving wellbeing.

Grief Australia has a particular interest in section 1b of the terms of reference, namely the *measurements of quality of life and wellbeing in New South Wales*.

## Executive Summary

As a leading provider of support and advocacy services for Australians suffering from Prolonged Grief Disorder, Grief Australia supports the NSW Parliament's desire to find opportunities, processes, and governance arrangements that would improve the measurement of quality of life and wellbeing in NSW.

We provide expert support and services at the crisis end of the wellbeing spectrum and have a strong interest in the prevention and measurement aspects.

The Australian Bureau of Statistics reports that there were 49,314 registered deaths in NSW in 2022.<sup>1</sup> This would have led to an estimated 443,826 bereaved residents in NSW in that year alone. It is further estimated that 1 in 10 bereaved people will develop Prolonged Grief Disorder.<sup>2</sup>

Prolonged Grief Disorder (PGD), as described by the 2022 Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR)<sup>3</sup> is '*intense and persistent grief that causes problems and interferes with daily life*.' Individuals with PGD experience significant distress or problems performing daily activities at home, work, or other important areas. The persistent grief is disabling and affects everyday functioning in a way that typical grieving does not. It can severely impact a person's emotional, social, financial, and physical wellbeing.

Beyond the loss of loved ones, residents of NSW are arguably facing more social and economic events that impede their overall wellbeing. This is inclusive of financial stress from increasing cost-of-living pressures; feelings of social isolation triggered by the COVID-19 pandemic and lasting to today; statewide natural disasters, and multiple terror attacks. These events can all trigger the onset of Prolonged Grief Disorder.

There is currently minimal support for Prolonged Grief Disorder funded by the NSW Government, and there is no standard policy around supporting individuals who find themselves in this situation. To that end, Grief Australia proposes the following recommendations to bolster the NSW response and improve the overall wellbeing of our residents.

<sup>1</sup> <https://www.abs.gov.au/statistics/people/population/deaths-australia/latest-release#:~:text=Media%20releases-.Key%20statistics,by%2051%20deaths%20to%20958.>

<sup>2</sup> [https://www.psychiatry.org/patients-families/prolonged-grief-disorder#:~:text=In%20addition%2C%20the%20person's%20bereavement,et%20al.%2C%202021\).](https://www.psychiatry.org/patients-families/prolonged-grief-disorder#:~:text=In%20addition%2C%20the%20person's%20bereavement,et%20al.%2C%202021).)

<sup>3</sup> American Psychiatric, A. (2022). *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR)* (Fifth Edition, Text Revision ed.). <https://doi.org/10.1176/appi.books.9780890425787>

## Recommendations

1. Formal data collection – to understand how many NSW residents suffer from Prolonged Grief Disorder and investigate the social and economic environment that triggers the onset of grief and which can help people recover from it.
2. Development of a NSW Prolonged Grief Management Plan in alignment with international best practices, which can be adopted by the NSW Government. This could be a standalone plan or part of a broader mental health, health or bereavement strategy. The plan should include:
  - Benchmarking and measurement
  - Support for General Practitioners and other health professionals in identifying and responding to complex bereavements
  - Achievable targets in terms of reducing the incidence
  - Tangible actions that support the achievement of the targets
  - Funding to drive the incidence of Prolonged Grief Disorder via specific, evidence-based services, either in isolation or as a subset of mental health services – including as part of the emergency preparedness and community resilience programs.
3. Grief management training should be formally included in public service human resources programs.

## Grief Australia Background

Grief Australia is Australia's leading voice on grief and provides evidence-informed grief therapy and education services. Our organisation has the expertise and experience to assist grieving Australians and partner with the NSW Government to improve NSW's response to grief.

Grief Australia is the largest national provider of bereavement counselling services and education in Australia and operates on three distinct policy foundations:

- Education and health promotion
- Clinical and support services
- Advocacy, Research and Consultancy Services

Grief Australia has a sustained history of supporting populations following numerous adverse events. This is inclusive of:

- Successfully delivering a federally funded \$5M national grief and bereavement program for aged care staff, family, and residents impacted by COVID-19.
- Worked in partnership with clinicians and governments to provide specialist bereavement support services following the 1997 Thredbo landslide, the 2002 Bali bombings, the 2004 Indian Ocean tsunami and deaths as a result of the disappearance of Malaysian Airlines Flight 370 in March 2014 and the destruction of Malaysia Airlines Flight 17 in July 2014.
- In partnership with the Victorian Government, we delivered a five-year support program following the February 2009 Black Sunday Bushfires.
- We have worked with numerous state governments across Australia in relation to the introduction of Voluntary Assisted Dying legislation and the unique bereavement needs of adults and children impacted by these deaths.

Grief Australia extends beyond death-related losses; we provided support to three local government areas that were impacted by the financial collapse and subsequent liquidation in 2002 of Ansett Australia. We focused on providing specialist support to flight crew, cabin staff, and ground staff through programs delivered via local government-facilitated initiatives.

## Understanding Social and Economic contexts that trigger Grief Disorder

While the loss of a loved one is the leading cause of the development of Prolonged Grief Disorder, from our professional experience, there are confounding factors that increase the prevalence of the disorder in the general population.

The feelings of grief and loss can be triggered by the generalised feeling of *'losing the illusion of control and predictability of life.'*

### Natural Disasters

It is clear from our learnings from supporting families and individuals affected by bushfires and floods across Australia that there is some level of immediate support available but a great lack of long-term support. The loss of a loved one or the loss of one's livelihood can and likely will have profound long-term effects. It is important that we have services set up to support these people through their grief journey.

Long-term grief support should be a standing pillar of the NSW Government disaster preparedness and community resilience programs. We hope to partner with the government to ensure that adequate fall-back services are available.

## Financial Stresses

With the extensive spikes in interest rates triggered by the inflationary economy, many are struggling with their financial situations. The inability to plan and predict how they will support their families and themselves in the future has profound effects on a person's mental health.

If financial stress is coupled with the loss of a home, employment, or a loved one, it creates an environment for the onset of grief disorder. There has been research that demonstrates increased rates of mental illness in times of economic recession<sup>4</sup>.

While there are hopes in the coming months for cost-of-living relief, there is a higher likelihood of continued interest rate rises. Potentially worsening the current financial stress and increasing the risk of people losing their homes.

## COVID-19

Our sector has had extensive learning from the unprecedented COVID-19 pandemic. While Australia recorded low levels of infections, in comparison to the world, we had some of the longest and most restrictive lockdown periods. The combination of death during this lockdown period, coupled with the loneliness of social isolation, has had profound impacts on mental health.

A 2024 Australian study by Maccallum and colleagues<sup>5</sup> found that nearly 20% of their participants reported feelings of grief that were associated with the loss of a loved one or were a result of their extended social isolation. The majority of the sample of participants reported increased feelings of prolonged loneliness that negatively impacted their wellbeing.

The findings of this above study and others that are emerging post pandemic should be considered when the government develops plans that are associated with improving the mental health of NSW residents and/or drafting pandemic plans for possible future events.

## Measuring and Reporting on Disordered Grief

While we understand the range of social and economic contexts that contribute to the onset of Disordered Grief, we do not have formal data collection to understand the real prevalence of the issue.

While a 2020–2022 survey by the ABS collected data on numerous mental disorders, including: Depression, Mania, Panic Disorder, Social Phobia, Agoraphobia, Generalised Anxiety Disorder, Substance Use, Obsessive–Compulsive Disorder, Post–Traumatic Stress Disorder – they did not include Grief Disorder as part of the scope of the study<sup>6</sup>.

Grief Australia recommends that the government invest in a study dedicated to understanding the number of residents of NSW who are impacted by the disorder. Grief Australia welcomes the opportunity to partner with the government and the primary care sector to undertake this research task.

If we are able to understand the real prevalence of bereavement support needs and Prolonged Grief Disorder in NSW – it will help improve and bolster grief services that are provided to the community. For example, if the data reflects higher levels of grief in certain areas where English is predominately a second language, we will consider that any increased services are sensitive to the cultural needs of that population.

Formal data collection will help our State understand the severity of the disorder, the distribution of cases, and the policies and strategies we develop to help support individuals or communities that are impacted by grief and/or Prolonged Grief Disorder.

<sup>4</sup> <https://bmcpublihealth.biomedcentral.com/articles/10.1186/s12889-016-2720-y#:~:text=The%20evidence%20was%20consistent%20that,related%20disorders%2C%20and%20suicidal%20behaviours>.

<sup>5</sup> Maccallum, F., Breen, L. J., Phillips, J. L., Agar, M. R., Hosie, A., Tieman, J., DiGiacomo, M., Luckett, T., Philip, J., Ivynian, S., Chang, S., Dadich, A., Grossman, C. H., Gilmore, I., Harlum, J., Kinchin, I., Glasgow, N., & Lobb, E. A. (2024). The mental health of Australians bereaved during the first two years of the COVID-19 pandemic: A latent class analysis. *Psychol Med*, 54(7), 1–12. <https://doi.org/10.1017/S0033291723003227>

<sup>6</sup> <https://www.abs.gov.au/methodologies/national-study-mental-health-and-wellbeing-methodology/2020-2022>

## An Action Plan to Drive Down Incidence of Grief Disorders

Furthermore, the data collected could inform the development of a NSW Grief Management Plan in alignment with international best practices, which can be adopted by NSW Government Services.

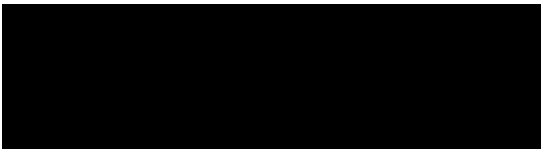
This plan can be used to draft and implement grief support policies for public service organisations, including but not limited to: NSW Police, Transport NSW, Teach NSW – Department of Education, and NSW Health. The overarching aim of the policy should be to support employees and their families who may either be bereaved or suffering from Prolonged Grief Disorder.

The plan should include:

- Benchmarking and measurement
- Achievable targets in terms of reducing the incidence
- Tangible actions which support the achievement of the targets
- Funding to reduce the incidence of Prolonged Grief Disorder via specific, evidence-based services, either in isolation or as a subset of mental health services – including as part of the emergency preparedness and community resilience programs.

Grief Australia welcomes the opportunity to co-design this Grief Management Plan with the NSW Government.

Yours faithfully,



Christopher Hall AM  
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