



Suicide Prevention  
Australia

JULY 2023

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# **Inquiry into the recognition of unpaid carers**

Submission

## Introduction

Suicide Prevention Australia welcomes the opportunity to provide input to the Inquiry into the recognition of unpaid carers. Suicide Prevention Australia is the national peak body for the suicide prevention sector. We have over 370 members representing more than 140,000 employees, workers, and volunteers across Australia. We provide a collective voice for service providers, practitioners, researchers, local collaboratives, and people with lived experience.

Over 3,000 people tragically die by suicide and an estimated 65,000 people attempt suicide each year. Over 7.5 million Australians have been close to someone who has taken or attempt suicide. Our shared vision is a world without suicide and with our members, we work to inform through data and evidence; influence systemic changes that drive down suicide rates and build capability and capacity for suicide prevention.

There is a growing recognition that risk of suicidality is a key concern for unpaid carers in our society. International research reported the number of carers experiencing suicidal ideation ranged up to 71%. [1] Other research has indicated that 1 in 6 carers are likely to attempt suicide, and 1 in 10 carers have attempted suicide. [2]

Carers are more than twice as likely to have low wellbeing and higher rates of psychological distress compared to the average Australian. [3] It is estimated there are 2.8 million informal unpaid carers in Australia, including 906,000 primary carers and 1.9 million non-primary carers in 2020. [4]

In our annual State of the Nation in suicide prevention survey, which gathers data on the needs of the suicide prevention sector in Australia, 46% of respondents identified carers are a population group requiring further support. [5]

Despite this, governments have yet to invest in targeted suicide prevention initiatives for carers. This may be due to the rapidly emerging nature of the evidence as much of the research on suicide risk in carers has been conducted in the last ten years.

However, there is now sufficient evidence to declare carers a high-risk population for suicide and an urgent priority for governments to take clear, decisive action to support at-risk carers and those for whom they care.

Our submission will respond to the following Terms of Reference:

1. the effectiveness of the Act and the associated Statement of Australia's Carers in raising recognition and awareness of the unpaid caring role, including its obligations on public service agencies
2. developments in the policy landscape at a Commonwealth level since the Act's passage in 2010
4. how to better identify the role of unpaid carers in Australian society and the role of a reformed Act, with regard to:
  - understanding the value of unpaid care,
  - the needs of specific cohorts
  - the meaningful role that flexible workplaces play in unpaid care, and
  - the Government's broad agenda in relation to the care and support economy, the importance of employment participation, and a strong focus on gender equity

## Summary of Recommendations

1. The Carer Recognition Act to be amended from 'recognising' unpaid carers to 'recognising and valuing' unpaid carers.
2. The Carer Recognition Act to be amended to expressly bind all public service agencies to compliance with the Act and omit the definition of 'public service care agency'.
3. The Carer Recognition Act to be amended to specifically promote inclusion of carer lived experience in leadership, policy decision-making, and service design related to the needs of unpaid carers.
4. The Parliamentary Committee on Social Policy and Legal Affairs to hold public hearings inviting unpaid carers to contribute to this Inquiry. The Committee should provide appropriate supports to ensure the wellbeing and safety of carers during hearing proceedings.
5. Commonwealth Government to co-design with carers a National Carer Strategy which adopts a holistic and social determinants approach to supporting the mental and physical health and wellbeing of carers support by funding for implementation of evidence-based supports for carers.
6. Commonwealth Government to establish a National Office of Carers to provide national coordination for carers' health, and integrate policy, legislation and programmes for all carers. A National Office for Carers should:
  - a. Be responsible for developing and implementing a National Carer Strategy.
  - b. Appoint a National Carer Lived Experience Advisory Group to oversee the National Carer Strategy and advise relevant Minister(s) on issues impacting unpaid carers.
  - c. Ensure representation and inclusion of the diversity of carers and of caring experience across the lifespan is represented in a National Carer Lived Experience Advisory Group.
  - d. Appoint a Director of Carer Lived Experience to ensure lived experience leadership is integral to the work of the Office, and work in collaboration with a National Carer Lived Experience Advisory Group.
7. Commonwealth Government to recognise status as an unpaid carer as a protected attribute in development of a new human rights framework for Australia.
8. The Carer Recognition Act to be amended to include a statement reflecting the intersectionality of carer identities and that discrimination, racism, ageism, and ableism can contribute to poor health outcomes among carers.
9. Commonwealth Government to introduce a Carers' Income Tax Offset (CARITO) to be credited against any income tax payable upon carers return to work after caring for children, people with a disability or elderly parents, in recognition of the value of their unpaid caring work.
10. Commonwealth Government to develop guidelines for supporting young carers and resources and posters in partnership with young carer organisations and young carers to be distributed and displayed in all schools, TAFE and universities, sporting clubs, GP clinics, and headspace services to encourage responsiveness to the support needs of young carers, and to help young carers identify whether they need support and where to find it.
11. Commonwealth Government to invest in national support to prevent suicide among all carers, including people who have attempted suicide or are impacted by suicidal distress. This should include funding free suicide intervention training to all carers in Australia.
12. States and territories to invest in the development and widespread implementation of training for healthcare professionals and all public service agencies in understanding risk of suicide among carers, and suicide prevention for carers. Training should be developed with carers and experts in carer suicidality.
13. Commonwealth Government to fund a national community education campaign led by a National Office of Carers in consultation with peak bodies and key organisations providing service to carers, to address stigmatisation of care, help identify the different types of caring and diversity of carers, knowledge of carer rights, and pathways to support.
14. Commonwealth Government to develop and maintain ongoing public awareness and education campaigns to address ageism and ableism which drive discrimination and stigma across unpaid care, health, education, employment, and social and cultural domains.
15. Commonwealth Government through the ABS undertake a national survey into the health and wellbeing of carers, including suicidal behaviours and key risk factors for suicide.
16. States and territories to record and report on deaths by suicide and suicide attempts among carers and former carers through their Suicide Deaths Registers and other reporting systems including the Australian Bureau of Statistics and the National Coronial Information System.

# 1. Effectiveness of the Carer Recognition Act 2010

The Carer Recognition Act 2010 (the Act) and supporting document Carer Recognition Act Guidelines (the Guidelines) outlines the obligations for public service agencies for implementation of the Act. However, the Guidelines clearly state that while compliance is highly desirable, 'the Act does not create any rights or duties that are legally enforceable'. [8]

Definitions in the Carer Recognition Act	
Public service agency	means an Agency within the meaning of the Public Service Act 1999.
Public service care agency	means a public service agency that is responsible for the development, implementation, provision or evaluation of care supports.

The obligations outlined in the Guidelines for public service agencies are limited to awareness of the Act and integrating the Act into internal human resources policies, whereas obligations for public service care agencies extend to taking practicable measures to take action to reflect the principles of the Act and undertake consultation with carers when developing or evaluating care supports. [9]

Supporting the psychosocial and socio-economic needs of carers extends beyond care providers. Carers experience challenges in navigating and accessing social services both for themselves and the person they care for, transport (particularly for carers in regional, rural and remote areas) which can impact loneliness and social isolation, and employment and education opportunities. A whole of government approach that addresses the social determinants that can lead to suicide is required to better support Australia's unpaid carers.

While the Carer Recognition Act sets out the human rights of carers, the Act itself has not been effective in enhancing the health and wellbeing, and social and economic opportunities of carers which can be significantly impacted by the level of unpaid care they provide.

The Act should reflect a whole of government and social determinants approach to upholding the rights of carers, with all government agencies required to consider the needs and impact of their policies and service provision on carers. The Act needs to progress from 'recognition' to valuing unpaid carers and ensuring they are well supported and have equal opportunity in socio-economic participation.

Carer lived experience should be integral to all policy and service design of carer supports. The Act currently acknowledges lived experience but is limited to partnering in the provision of care (Schedule 1.7). Carers should have the opportunity to be heard in this Inquiry through the provision of a series of hearings, with appropriate supports in place to protect the safety of carers, and of those they care for.

## Recommendations:

1. The Carer Recognition Act to be amended from 'recognising' unpaid carers to 'recognising and valuing' unpaid carers.
2. The Carer Recognition Act to be amended to expressly bind all public service agencies to compliance with the Act and omit the definition of 'public service care agency'.
3. The Carer Recognition Act to be amended to specifically promote inclusion of carer lived experience in leadership, policy decision-making, and service design related to the needs of unpaid carers.
4. The Parliamentary Committee on Social Policy and Legal Affairs to hold public hearings inviting unpaid carers to contribute to this Inquiry. The Committee should provide appropriate supports to ensure the wellbeing and safety of carers during hearing proceedings.

## 2. Developments since the Carer Recognition Act 2010

In 2011 Australia released its first National Carers Strategy 2011-2014 which aimed to ensure that the Australian community understands the needs of carers, and guide policy reform to strengthen support for carers to continue caring. The Strategy expired in 2014 and Australia has not adopted another national strategy to address the health and wellbeing of carers since.

It is estimated that if carers stopped caring for people with profound disability, it could account for \$77.9 billion replacement value on the Australian economy. [10] Our consultations identified that in some cases, carers are continuing to provide high level care to supplement supports provided through the National Disability Insurance Scheme.

As the demand for informal care is predicted to grow from approximately 1.25 million in 2020 to 1.54 million in 2030 (23% increase), there is a significant need for national coordination of carer suicide prevention that addresses key risk factors for carers, to build capacity for coping and resilience more broadly across communities. [11]

The Commonwealth Government recently held an Inquiry into Australia's Human Rights Framework in 2023. The status of unpaid carers should be recognised as a protected attribute in the development of a new human rights framework.

### Recommendations:

5. Commonwealth Government to co-design with carers a National Carer Strategy which adopts a holistic and social determinants approach to supporting the mental and physical health and wellbeing of carers support by funding for implementation of evidence-based supports for carers.

6. Commonwealth Government to establish a National Office of Carers to provide national coordination for carers' health, and integrate policy, legislation and programmes for all carers. A National Office for Carers should:

- a. Be responsible for developing and implementing a National Carer Strategy.
- b. Appoint a National Carer Lived Experience Advisory Group to oversee the National Carer Strategy and advise relevant Minister(s) on issues impacting unpaid carers.
- c. Ensure representation and inclusion of the diversity of carers and of caring experience across the lifespan is represented in a National Carer Lived Experience Advisory Group.
- d. Appoint a Director of Carer Lived Experience to ensure lived experience leadership is integral to the work of the Office, and work in collaboration with a National Carer Lived Experience Advisory Group.

7. Commonwealth Government to recognise status as an unpaid carer as a protected attribute in development of a new human rights framework for Australia.

## 4. The role of a reformed Act

### Understanding who carers are is key to identifying carers

Carers are a diverse population from a variety of backgrounds facing a range of challenges additional to caring responsibilities. Approximately 1 in 3 carers are primary carers (providing the most care on one or more daily living activities) and are most commonly female and middle aged. [12] While majority of carers are female and middle aged, the number of male primary carers aged 75 years and over is similar to the number of females aged 75 years and over (45,300 males and 44,400 females). [13] Primary carers are also more likely to live with a disability themselves compared to non-carers. [14]

Between 25% and 30% of Australian carers identify with culturally and linguistically diverse backgrounds [15], 12.4% of carers are First Nations peoples (compared to 10.5% of non-Indigenous Australians) [16], between 15-30% of lesbian, gay, bisexual, and transgender people are carers [17], and there are more than 235,000 young carers in Australia. [18] Carers may also be grandparents who have taken on a primary carer role for children due to family relationship breakdowns where parents are unable to care for their children.

The Carer Recognition Act should reflect intersectionality of identities and recognise that discrimination, racism, ageism and ableism can contribute to poor health outcomes among carers.

### Recommendation:

8. The Carer Recognition Act to be amended to include a statement reflecting the intersectionality of carer identities and that discrimination, racism, ageism, and ableism can contribute to poor health outcomes among carers.

## The value of unpaid care

Gender inequality is prevalent among carers, with women more likely to be unpaid carers than men. [19] KPMG reported that one-third of the difference in pay outcomes for men and women can be attributed to time spent caring for family and career interruptions from the workforce. They estimate that when the value of unpaid caring work is combined to the value of paid work, women do more than half of all the work performed in Australia. [20]

The estimated annual replacement value of all unpaid care in Australia has grown by 29% since similar research was conducted in 2015. [21] The current estimated value equates to approximately \$1.5 billion per week to the Australian economy. [22] Since 2018, the number of unpaid carers in Australia has increased by 5.5%. [23]

Many carers do not have a choice in the level of care they provide due to gaps in the healthcare system or the NDIS which do not fully meet the needs of the person they care for. When a significant level of care has to be provided, many carers leave the paid workforce to dedicate the required time needed for the person they care for.

When carers leave the paid workforce due to caring responsibilities, there should be supports in place to encourage re-entering the paid workforce when possible.

KPMG recommend introducing a Carers' Income Tax Offset (CARITO) which would value the time spent performing unpaid caring duties while out of the paid workforce, and be payable upon carers returning to work after a period of unpaid caring. KPMG advise this model would be similar in design to the Low and Middle Income Tax Offset and not be gender specific. Given women do most of the unpaid caring in Australia, it would have additional benefits to addressing the gender inequality.

### Recommendation:

9. Commonwealth Government to introduce a Carers' Income Tax Offset (CARITO) to be credited against any income tax payable upon carers return to work after caring for children, people with a disability or elderly parents, in recognition of the value of their unpaid caring work.

## Need for targeted suicide prevention among carer populations

Data from the Australian Longitudinal Study on Women's Health showed that among women providing unpaid care 7.1% (n=3077) had felt life was not worth living in the previous week, significantly more than 5.7% of non-carers. [24] Males aged over 85 years had the highest age-specific suicide rate accounting for 3.2% of suicide among males in 2021. [25]

Australian research of 566 people caring for family members with dementia found that 16% experienced thoughts of suicide more than once in the previous 12 months (four times the national average for suicidal ideation). [26] A study on factors associated with high psychological distress of carers of people with a disability found 27% of carers had high psychological distress, and when carers had a closer relationship with the person they care for, psychological distress was elevated by 50%. [27]

Young carers have been found to have increased risk of mental health difficulties, particularly in situations where the person they care for was a parent with mental illness or substance misuse issues. [28]

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## Case Study: Young Carer for Parent with Mental Illness

Authored by Person with Lived Experience

I was an informal carer to my mother from the ages of 12 years to early adulthood. By informal, I mean that I was not identified or recognised by any formal organisation, system or supports at the time, however I fit the definition of carer as described by Carers Australia. My mother was a consumer, she was a person living with mental illness and was in receipt of professional treatment for this, although disagreed with her diagnosis and mostly chose not to accept treatment. I provided my mother with support in daily activities including personal care when she was very unwell, and addressed much of the household tasks (cleaning, shopping, cooking, finances etc). When my mother was suicidal this care extended to emotional support and accessing doctors and emergency services.

I also experienced family violence from my mother and coercive control was a key characteristic of this violence. I received no support from extended family or any services in helping me to care for my mother.

The caring responsibilities, and feeling overwhelmed and isolated, took a heavy toll on my ability to be a normal child. I never saw friends outside of school days, never went out of the house on family activities, and had a constant feeling of sadness. I felt responsible for keeping my mother alive. It adversely affected my education by having a high non-attendance rate, and as well I was not afforded the space or privacy after school hours to complete homework as my mother's needs were always the priority. When I was aged 16 years I disclosed to a school counsellor about the situation, and the counsellor merely told me there was nothing they could do. After this experience, I never disclosed the situation to anyone else until later in my adulthood.

When I was 15 years old, I made my first attempt to take my life. I had been through several weeks of supporting my mother through a significant deterioration in her mental health as well as experiencing family violence in some form on a daily basis. The attempt failed and I never discussed it with anyone at the time. I was physically unwell for several days after and never sought medical help for this.

There are many complexities around caring for a parent with a mental illness. Mental illness affects people in different ways, and as well can adversely affect relationships by way of the person with the diagnosed illness having high and complicated needs which can become overwhelming for carers, particularly if the family unit is socially isolated as mine was. Mental illness also is still stigmatised, and young people may not wish to disclose what is going on for them at home, as was the case for me. Hence there are many barriers to young carers help-seeking which requires a better understanding in general.

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Additional factors that can lead to increased risk of suicidality in carers are varied, and may be influenced by:

- the chronicity and severity of suicidal distress of the care recipient will impact the type of support required by the caregiver
- the length of time the carer has provided care will influence the type of information required
- the type, quality, and closeness of relationship between the carer and care recipient

Carers experience a range of physical, psychological, and financial challenges as result of the demands involved in providing care to the people they care for, and as such can also experience social isolation, loneliness, and financial distress – all of which are key risk factors for suicide. [29]

These risk factors for suicide are further heightened for carers living in regional, rural, and remote Australia. The 2016 Regional Wellbeing Survey identified 15% of adults living in regional areas reported being carers. [30] 29% of regional carers felt isolated due to their caring role, 42% experienced financial stress, and 35% had either stopped or reduced employment due to their caring role. [31]

Primary carers can spend more than 60 hours per week caring, meaning that many forgo protective factors for suicide such as employment, which provides a sense of purpose and financial independence. [32] In 2020 the estimated age-standardised full time employment rate for primary carers is 23.7% compared to 43.1% of the general population. [33]

If Australia is to meaningfully support unpaid carers, the Australian Government must invest in the social determinants of health that lead to increased distress including unemployment, housing, transport, and social services.

### **Recommendations:**

10. Commonwealth Government to develop guidelines for supporting young carers and resources and posters in partnership with young carer organisations and young carers to be distributed and displayed in all schools, TAFE and universities, sporting clubs, GP clinics, and headspace services to encourage responsiveness to the support needs of young carers, and to help young carers identify whether they need support and where to find it.

11. Commonwealth Government to invest in national support to prevent suicide among all carers, including people who have attempted suicide or are impacted by suicidal distress. This should include funding free suicide intervention training to all carers in Australia.

12. States and territories to invest in the development and widespread implementation of training for healthcare professionals and all public service agencies in understanding risk of suicide among carers, and suicide prevention for carers. Training should be developed with carers and experts in carer suicidality.

13. Commonwealth Government to fund a national community education campaign led by a National Office of Carers in consultation with peak bodies and key organisations providing service to carers, to address stigmatisation of care, help identify the different types of caring and diversity of carers, knowledge of carer rights, and pathways to support.

14. Commonwealth Government to develop and maintain ongoing public awareness and education campaigns to address ageism and ableism which drive discrimination and stigma across unpaid care, health, education, employment, and social and cultural domains.

### **Need for better data collection**

Although the existing evidence on suicide risk in carers is compelling, there is a need for more specific data on carers in Australia. This may be particularly pertinent for carers (or those for whom they care) whose identities and experiences intersect with other high-risk groups (e.g. veterans, Aboriginal and Torres Strait Islander people, LGBTQIA people, people with complex trauma, carers who have survived a suicide attempt) and so place them at even greater risk of suicide than other carers.

It is important to ensure that the evidence includes not only suicidal thoughts and suicide attempts, but also deaths by suicide. Suicide death datasets currently do not report on whether the person was a carer for another person, limiting our understanding of suicide death rates among carers in Australia.

State and territory suicide deaths registers contribute data to the national Suicide and Self-harm Monitoring System which assists in providing a national dataset on suicide in Australia. Suicide death registers should record and report on suicide deaths by carers and former carers, and the Australian Bureau of Statistics should include carers in reporting on psychosocial risk factors for suicide studies.

The National Study of Mental Health and Wellbeing recently published in 2022 did not provide any breakdown of psychological distress or experience of suicide data on carers. While the Australian Institute of Health and Welfare provide some data on the lives of carers, there is not data reported on the experience of suicidality among carers.

Without knowing exactly how many carers are lost to suicide each year, it is challenging for governments and sectors to target suicide prevention funding and efforts to supporting carers.

### **Recommendations**

15. Commonwealth Government through the ABS undertake a national survey into the health and wellbeing of carers, including suicidal behaviours and key risk factors for suicide.

16. States and territories to record and report on deaths by suicide and suicide attempts among carers and former carers through their Suicide Deaths Registers and other reporting systems including the Australian Bureau of Statistics and the National Coronial Information System.

## **Acknowledgements Statement**

Suicide Prevention Australia acknowledges the unique and important understanding provided by people with lived and living experience. This knowledge and insight is critical in all aspects of suicide prevention policy, practice and research. Advice from individuals with lived experience helped guide the recommendations outlined in this policy position. We thank the person with lived experience for writing and sharing their experience for inclusion as a case study in this submission.

As the national peak body for suicide prevention, our members are central to all that we do. Advice from our members, including the largest and many of the smallest organisations working in suicide prevention, as well as practitioners, researchers and community leaders is key to the development of our submissions. Suicide Prevention Australia thanks all involved in the development of this submission.

## **If you or someone you know require 24/7 crisis support, please contact:**

**Lifeline: 13 11 14**

[www.lifeline.org.au](http://www.lifeline.org.au)

**Suicide Call Back Service: 1300 659 467**

[www.suicidecallbackservice.org.au](http://www.suicidecallbackservice.org.au)

## **For general enquiries**

02 9262 1130 | [policy@suicidepreventionaust.org](mailto:policy@suicidepreventionaust.org) | [suicidepreventionaust.org](http://suicidepreventionaust.org)



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