

# SUICIDE AMONG CARERS

## POLICY POSITION

October 2022

### POSITION

1. Commonwealth Government to codesign with carers a National Carer Strategy which adopts a holistic approach to supporting the mental and physical health and wellbeing of carers with funding attached for implementation of evidence-based supports for carers. The Commonwealth Government should consult the National Office of Suicide Prevention in development of a National Carer Strategy.
2. 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 such as ASIST to all carers in Australia.
3. Commonwealth Government in partnership with states and territories to invest in a national equitable respite care scheme for carers and people receiving care to meet existing gaps in respite care.
4. Department of Social Services and Services Australia to review legislation, and policy and procedural guidelines, to identify and address issues affecting accessibility of the Carer Payment and Carer Allowance for carers with a view to recognising the impact caring has on their ability to maintain employment. The review should particularly focus on issues relating to the episodic nature of psychosocial disability.
5. States and territories to invest in the development and widespread implementation of training for healthcare professionals in understanding risk of suicide among carers, and suicide prevention for carers. Training should be developed with carers and experts in carer suicidality.
6. Commonwealth Government through the AIHW undertake national data collection into the health and wellbeing of carers.
7. 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.
8. The Commonwealth Government to review The Adult Disability Assessment Tool (ADAT) outlined in the Adult Disability Assessment Determination 2018 legislation with a view to better assessing the impacts of psychosocial disabilities.

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## CONTEXT AND COMMENTARY

The Carer Recognition Act 2010 defines carers as individuals who provide care, support and assistance to people who have a disability, medical condition, mental illness, or are frail and aged.<sup>1</sup> Paid care workers, sometimes referred to as 'carers' are people formally employed under contract to provide care to a person and are not addressed in the scope of this position. The ABS reported 1 in 10 (2.65 million) Australians provided informal care in Australia in 2018.<sup>2</sup> The total cost estimated to replace informal care in 2020 was \$77.9 billion in Australia.<sup>3</sup>

There is a growing recognition that risk of suicidality is a key concern for this important group in our society. An international scoping review found the number of carers experiencing suicidal ideation ranged up to 71%, and further reported evidence of suicide attempts and deaths with 1 in 6 carers likely to attempt and 1 in 10 carers already having attempted suicide.<sup>4</sup> Carers are more than twice as likely to have low wellbeing and higher rates of psychological distress compared to the average Australian.<sup>5</sup>

In our annual State of the Nation in suicide prevention survey addressing the needs of the suicide prevention sector in Australia, 46% of respondents identified carers are a population group requiring further support.<sup>6</sup> 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.

It is important to acknowledge that carers are a diverse group coming from a variety of backgrounds and facing a range of challenges. Approx. 1 in 3 carers are primary carers (provide the most care on one or more daily living activities) and are most commonly female and middle aged.<sup>7</sup> Between 25 and 30% of Australian carers are from culturally and linguistically diverse backgrounds,<sup>8</sup> 12.4% of Aboriginal and Torres Strait Islander people are carers (compared to 10.5% of non-Indigenous Australians)<sup>9</sup>, between 15-30% of LGBT people are currently in caring roles,<sup>10</sup> and there are more than 235,000 young carers in Australia.<sup>11</sup>

It is also important to acknowledge that the 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

The evidence on suicide risk in carers spans care provided in respect of people with a range of illnesses and disabilities, including but not limited to cancer, autism, HIV, schizophrenia, quadriplegia, down's syndrome, and cerebral palsy.<sup>12</sup> Data from the Australian Longitudinal Study on Women's Health showed that among women providing unpaid care (n=3077) 7.1% had felt life was not worth living in the previous week, significantly more than 5.7% of non-carers.<sup>13</sup>

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In addition, an Australian study 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).<sup>14</sup> 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%.<sup>15</sup>

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.<sup>16</sup> 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.<sup>17</sup> Carers who live in regional and remote areas face challenges in accessing support due to a lack of services in the region, lack of public transport, and distance required to travel to access support services or support from friends and family.

In addition to the above, carers experience a range of physical, psychological, and financial challenges as a result of the demands involved in providing care to their relatives and friends, and as such can experience high rates of psychological distress, social isolation, loneliness, and financial distress – all of which are key risk factors for suicide.<sup>18</sup> In addition to targeted support addressing the range of different factors that may be involved in each carer's journey, these risk factors must be addressed to reduce the numbers of carers experiencing suicidality.

### **Nationally led suicide prevention for carers**

In recent years the Commonwealth has continued to invest funding in the Carer Gateway to help carers access available support services.<sup>19</sup> While pathway support for carers is needed, many carers are unable to seek support for themselves due to their caring responsibilities.

In 2018, 33% of carers were primary carers.<sup>20</sup> Through consultation, our members reported barriers to help-seeking. These include but are not limited to:

- Being unable to leave the person alone due to high level care needs
- Not seeking support for suicidal thoughts due to fear of having the person removed from their care
- As a result of previous experiences, lacking trust in services and having no hope that support will be provided
- Financial distress
- Limited time availability due to care provided
- Not identifying with the label 'carer' and as such less likely to identify support services which use this label
- Guilt and shame at prioritising their own needs over the person they care for.

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.

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Primary carers can spend more than 60 hours per week caring for their relative or friend, meaning that many forgo protective factors for suicide such as employment, which provides a sense of purpose and financial independence.<sup>21</sup> In 2020 the estimated age-standardised full time employment rate for primary carers is 23.7% compared to 43.1% of the general population.<sup>22</sup> It is estimated that if carers stopped caring for people with profound disability, it could account for \$51.6 billion replacement value on the Australian economy.<sup>23</sup> 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.<sup>24</sup> The Commonwealth should codesign with carers a National Carer Strategy which adopts a holistic approach to supporting the health and wellbeing of carers. This strategy must be accompanied by funding for implementation.

### **Targeted suicide prevention supports for carers**

Research shows that a lack of support and dysfunctional coping strategies are risk factors for suicide among carers.<sup>25</sup> We know that a suicide attempt is the strongest risk factor for subsequent suicide, and the risk for suicide after an attempt is significantly elevated compared to the general population.<sup>26</sup> Suicide attempts and suicidal distress have significant impacts not only on the individual experiencing suicidality but also on the carers, family and friends surrounding them. While aftercare services support survivors of suicide attempts and postvention supports those bereaved by suicide, there is a major gap in the support available to people impacted by a suicide attempt or suicidal distress. These carers, friends, families and communities are missing out and need support.

Carers are the closest support to people who have attempted suicide and who are in immediate risk of suicide, and as such it is critical suicide prevention to ensure carers are supported in their caring roles to not only continue to support their relatives and friends, but to help manage the impact of caring for someone experiencing suicidal behaviours has on their own wellbeing.

Crisis intervention training can be beneficial in supporting carers to equip them with the skills to respond to distress experienced by the person they care for. Support provided by carers, family and friends is a key protective factor for suicide and has been shown to have a direct positive effect on suicide ideation.<sup>27,28</sup> ASIST training uses a suicide intervention model and helps carers recognize when someone is at risk of suicide, and how to increase their safety and connect with further support.<sup>29</sup> ASIST training should be delivered to all carers in Australia free of cost.

There is a need for carer peer workers who have experience supporting someone who experiences suicidal behaviours. For carers to be able to access supports, targeted peer support programs should include support components for the person they care for simultaneously and provide outreach opportunities to meet the needs of the carer and their relative or friend.

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We support the Victorian Royal Commission into mental health recommendation (31) for the establishment of a family and carer-led centre in every region in the State that increasing capacity to work with families and carers to help identify needs and connect them with supports, provide increased funds for immediate practical needs (including short term respite care), and deliver support for family and carer peer support groups.<sup>30</sup> We believe this should be a nationally led initiative to be implemented by all jurisdictions across Australia.

In addition to targeted support programs for carers, short term respite care can help manage burnout from their caring responsibilities by providing temporary relief from stressors associated with their caring role and a positive experience for the person receiving care.

Prior to implementation of the National Disability Insurance Scheme (NDIS) carers were able to access respite care through national and state programs.<sup>31</sup> Most of the funding for those programs has been absorbed into the NDIS and those services are no longer available.<sup>32</sup> For programs that are still funded, carers become ineligible to access them if their person they care for is in the NDIS.<sup>33</sup> While this gap has in part been met by the Carer Gateway which provides free in-person or telephone support to carers, the need for respite care remains.

A key issue facing carers attempting to have respite care included in NDIS planning is the National Disability Insurance Agency's reluctance to use the word 'respite' due to advice that it is harmful language for people with disability.<sup>34</sup> Despite a recent reintroduction of the term respite to the NDIS (under the service type Short Term Accommodation, including respite), carers are still being informed it is not a service provided in the NDIS leaving them without access to respite care. For carers supporting people who require diagnosis to become eligible for the NDIS, it often takes significant time to acquire diagnosis. Interim supports for carers should be considered for those not yet eligible to access the NDIS.

It's important that the language for respite access in the NDIS is clearly communicated to carers, and that this be consistent across jurisdictions. Australia needs a coordinated national equitable respite care scheme which addresses the barriers carers face in accessing respite services to meet existing gaps in respite care.

### **Social security income supports can act as a protective factor for suicide**

In addition to the provision of targeted suicide prevention supports, it is essential to address key factors that can drive increased risk of suicidality. A significant issue in this regard is financial distress. Carers commonly experience financial distress due to reduced hours of employment or withdraw from work due to the demands of their caring responsibilities. The overall informal mental health support provided by primary and other carers was 186 million hours in 2018, which is estimated to the provision of at least AU\$8.4 billion in mental health support to the Australian economy.<sup>35</sup>

Employment has been found to be a protective factor for suicide among carers,<sup>36</sup> however evidence shows carers are more likely than non-carers to reduce their hours of work or exit from the labour force and earn a lower level of income.<sup>37</sup> Despite this, only 28% of Australian carers received Carer Payment.<sup>38</sup> Ensuring all carers have access to income support payments could mitigate suicide risk in this group and help carers to be more engaged in their communities, protect their own wellbeing, and provide better support for those whom they care for.

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The Adult Disability Assessment Tool (ADAT) is currently used to calculate level of care in assessment of Carer payment eligibility for carers in Australia. Whilst the ADAT may be generally appropriate, arguably, to determine the level of care requirement for people with physical disability, it fails to capture the provision of care needs among people with psychosocial disabilities. This creates barriers to Carer Payment access for people providing care for people with psychosocial disability.

The current criteria for conditions to extend more than 6 months to qualify for payment can prohibit carers' access to Carer Payment, particularly for those providing care to family members with mental illnesses that are episodic in nature. Carers often provide support in a range of areas across social, emotional, physical, and financial needs to the people they care for. These activities are not adequately measured by ADAT. Accessing income support payments for carers also requires providing documentation which can be costly and take significant time to gather, further adding to the burden of caring role and exacerbating some of the stressors that contribute to suicide risk.

There is a need to reform the Social Security Act, the ADAT and the Disability Care Load Assessment (Child) (DCLA) so as to enhance the accessibility of the Carer Payment and Carer Allowance for carers who support people with psychosocial disabilities (including episodic mental illness), acknowledging the impact that caring for a person with disability has on carer's ability to maintain employment. These legislative processes should be reviewed to include identifying structural and systemic barriers to accessing Carer Payment and Carer Allowance for Aboriginal and Torres Strait people, people living in regional and remote areas, people from CALD communities, young carers, carers with disability, ageing carers, carers of people whose care needs fluctuate, and people who share the care provided for a person.<sup>39</sup>

### **Australian research on carers is needed**

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 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.

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**There are crisis services available 24/7 if you or someone you know is in distress**

**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)

Imagine a world without suicide

## 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 analysis and recommendations outlined in this policy position.

Members from our Lived Experience Panel provided advice on the need for carer respite services, the inadequacies and barriers to accessing carer income support payments, the need for additional carer support services, and the need for suicide prevention training among healthcare professionals which are reflected in the recommendations, scope, and context of this position.

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 policy positions. Suicide Prevention Australia thanks all involved in the development of this policy position.