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Submission to the inquiry into the recognition of unpaid carers

Prepared by Everymind for the Parliament of Australia's Federal House of Representatives Standing Committee on Social Policy and Legal Affairs

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About Everymind

Everymind welcomes the opportunity to contribute to the inquiry into the recognition of unpaid caregivers. We are a leading institute dedicated to the prevention of mental ill-health and suicide, with a vision of empowering people and organisations to implement change - for themselves, for each other and for the future. We have a long-standing reputation for designing, implementing, and evaluating tailored policy advice, research and programs. This includes over two decades of experience designing and delivering programs, policy responses and translational research targeted at improving the mental health and wellbeing of families and friends¹. We provide a suite of programs and resources developed to support the mental health and wellbeing of those who care for someone experiencing mental health concerns or suicidal distress through our *Minds Together* program.

The concern

Mental health concerns and suicidal distress significantly impact individuals, families and communities. More than 40% of Australians will experience mental health concerns across their lifetime, over 3,000 people die by suicide and an estimated 65,000 Australians attempt suicide each year. Recent research indicates that the prevalence of mental health concerns and psychological distress is increasing. Most people experiencing distress will not seek formal help or will experience difficulties in accessing support. Family and friends therefore provide most of the practical and emotional support for those in distress, with the value of this care estimated at \$15 billion annually.

Providing support and care is a rewarding and valuable role. Still, the complexity and associated challenges of the caregiving role may lead to increased risk of mental health concerns and suicidal distress for family and friends themselves. Caregiving is also associated with reduced engagement with employment, financial difficulties and social isolation. Increased recognition and support of caregivers is critical to prevent the onset or worsening of mental ill-health and suicidality for both the person being supported and the caregivers themselves. Additional legal, structural, and other tangible support are required to improve the health and wellbeing of family and friends supporting someone experiencing mental health concerns or suicidal distress.

The response

The time is right to set a reform agenda in Australia that positions the mental health and wellbeing of unpaid carers as a national priority, requiring coordinated action across all settings and jurisdictions. Integral components of the current National Carer Recognition Framework have lapsed and a new whole-of-government National Carer Strategy is required. The recommendations outlined in this submission will address the following terms of reference of the inquiry:

1. Effectiveness of the *Carer Recognition Act 2010* 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 caregivers in Australian society and the role of a reformed Act.

¹ Everymind uses the terms 'family and friends' or 'caregivers' in place of the term 'carers'. This aligns with our research for *Our words matter: Guidelines for language use* (mindframe.org.au/our-words-matter-guidelines-for-language-use) and consistent feedback from those supporting someone experiencing mental health concerns or suicidal distress to not be referred to as 'carers'.

Summary of recommendations

1. Strengthen the *Carer Recognition Act 2010* to recognise the rights of caregivers and require public service agencies comply with the Act, as the current Act is not binding on any other Act.
2. The Australian Government work with caregivers and sector representatives to co-design, implement and monitor a new whole-of-government National Carer Strategy.
3. All jurisdictions work together to deliver a whole of government approach at national, state and regional levels, with national outcomes to be developed and adopted by all governments.
4. Regular national surveys to determine the prevalence of unpaid caregivers.
5. Increased public communication and awareness campaigns to improve public understanding about the role of caregivers.
6. A new National Carer Strategy include actions to reduce stigma associated with the caregiving role.
7. All jurisdictions implement training for frontline workers that enable them to identify caregivers and enable them to respond early to distress.
8. A new National Carer Strategy includes consultation with family and friends across all caregiving contexts about preferred language associated with their role and the use of the term 'carer'.
9. A new National Carer Strategy is developed to align with the National Agreement on Mental Health and Suicide Prevention.
10. The Australian Government integrate lived experience knowledge into the development, delivery and evaluation of the new National Carer Strategy.
11. All jurisdictions include caregivers in the development of early distress interventions.
12. A National Carer Strategy develops actions to integrate digital and face-to-face evidence-based support that address the unique factors of supporting someone experiencing mental health concerns or suicidal distress.

Background

Building the capacity and capability of caregivers is a critical part of a comprehensive mental health and suicide prevention approach.

Despite the high rates of mental health concerns and suicidal distress in Australia, many people are unable or reluctant to seek professional support. They are, however, more likely to access services if encouraged by family and friends. Caregivers are fundamental to promoting and sustaining recovery for those experiencing distress, yet they are largely excluded from the recovery planning process. The complexity of the caregiving role means that they are also at an increased risk of mental health concerns and suicidal distress themselves. Yet, there is limited availability and access to evidence-based services and support that focus on the mental health and wellbeing of caregivers.

Recurrent research identifies the unique opportunities and challenges of caregiving roles. Whilst rewarding, caregiving roles have been correlated with poorer health outcomes. In some instances, caregivers can experience higher rates of depression and anxiety than the person they are supporting. Disproportionate rates of stress, relational distress, loneliness, fatigue, neglect of own needs, and poorer physical, emotional and mental health outcomes are commonly associated with support and caregiving roles.

Furthermore, caregivers report lower quality of life, poorer sleep and less physical activity compared to the general population. Financial strain, reduced employment and employability, reduced recreation, and reduced familial life

and social contact are commonly reported by people in caring roles. Similarly, studies are showing that informal caregivers experience higher levels of suicidal distress.

Every major review undertaken in Australia in the past 12 months² has recognised the integral role of caregivers in preventing the development of mental ill-health and suicidal distress and recommended a significant increase in the provision of support to caregivers. Everymind has worked with family and friends to better understand their experience of being a caregiver and their needs. Access to strategies, tools and coping mechanisms have been identified as important supports for caregivers who have described feeling unsupported and can assist them in building skills and enhancing their mental health and wellbeing. Caregivers also report that access to evidence-based online programs is particularly helpful as they are able to access content at a time and place that best suits them. This is in line with a wide-ranging review undertaken by Everymind on the benefits of online support and face-to-face interventions for caregivers.

Terms of Reference 1: Effectiveness of the Carer Recognition Act 2010 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

In 2009, the Australian Government committed to the development of the National Carer Recognition Framework, consisting of the *Carer Recognition Act 2010*, the *National Carer Strategy* and associated *Action Plan (2011-2014)*.

Whilst the *Carer Recognition Act 2010* formally acknowledge the valuable social and economic contribution of family and friends in caregiving roles, caregivers in the Act are considered predominately in relation to the person they support, without adequate recognition of their specific needs.

The primary obligations outlined in the *Carer Recognition Act 2010* pertain to public service agencies. While compliance with obligations articulated in the Act is highly desirable, the Act does not create any rights or duties that are legally enforceable. The Act is therefore limited to raising awareness, consulting and reporting obligations. The Act does not recognise that caregivers underpin the sustainability of our health and social support systems, does not recognise the value of lived experience in developing policy and service systems that support caregivers, and does not promote a whole-of-government approach to address the needs of caregivers and the people they support.

Recommendation

1. Strengthen the *Carer Recognition Act 2010* to recognise the rights of caregivers and require public service agencies comply with the Act, as the current Act is not binding on any other Act.

Terms of Reference 2: Developments in the policy landscape at a Commonwealth level since the Act’s passage in 2010

The object of the *Carer Recognition Act 2010* and the Statement for Australia’s Carers (Schedule 1 of the Act) is to increase recognition and awareness of caregivers and ensure the valued contribution they make to society remains in place. The National Carer Strategy underpinning implementation of ten cornerstone principles outlined in the Act lapsed almost ten years ago. Since then, there has been a substantial increase in the demands on unpaid caregivers stemming from the COVID-19 pandemic, persistent natural disasters experienced in Australia over the past five years, and increased cost of living pressures. The impact of the caregiving role, including the negative

² Reviews include the Australian Government’s Productivity Commission Report into Mental Health, the National Suicide Prevention Advisor’s Final Report, the Royal Commission into Victoria’s Mental Health System and the Australian Parliament House of Representatives Select Committee on Mental Health and Suicide Prevention.

impact on caregiver's health and wellbeing have been identified by multiple government inquiries including the 2020 Productivity Commission Inquiry into Mental Health, the 2021 Royal Commission into Aged Care Quality and Safety, the 2021 National Suicide Prevention Advisor's final advice, the current Royal Commission into Defence and Veteran Suicide, and current Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. These inquiries all identified the significant gap that continues to exist between recommendations and real change that recognise caregivers as partners in the provision of social and health services.

Recommendations

2. The Australian Government work with caregivers and sector representatives to co-design, implement and monitor a new whole-of-government National Carer Strategy.
3. All jurisdictions work together to deliver a whole of government approach at national, state and regional levels, with national outcomes to be developed and adopted by all governments.

Terms of Reference 4: How to better identify the role of unpaid carers in Australian society and the role of a reformed Act

Identifying unpaid carers

Almost 13% of Australians aged over the age of 15 years provide unpaid care to a person with a disability, illness, chronic condition or age-related health condition. Caregivers come from very diverse age, gender, cultural, geographical and social backgrounds. Most are primary caregivers providing informal support to family or friends. They are female, middle aged, provide care for at least 20 hours per week, and are more likely to have a disability. However, these descriptors don't provide a comprehensive picture of unpaid caregivers in Australia. Evidence suggests that caregivers can be uncomfortable adopting a caregiver identity and using the carer label.

This aligns with our own research, including Everymind's 2019 consultation with friends and family who support someone experiencing mental health concerns which found that they are mostly as female, experience high levels of psychological distress, and are very invested in the wellbeing of the person they support. Many of these family and friends do not identify with the term 'carer'. In our 2023 research workshop with 52 people with lived and living experience of suicidal distress and family and friends from around Australia, we heard that 'family and friends', 'support person/people' and 'supporter' were preferred terms for someone providing support. 'Carer', 'caregiver', 'unpaid carer', 'loved one' and 'significant other' were not preferred terms.

The term 'carer' is broadly applied to all carer groups and there has been intense debate on whether it is helpful or problematic. Caregivers who adopt the carer label and engage in help seeking through caregiver programs or support groups are supported by government policies which promote self-identification as a strategic priority to recognise and support caregivers. Conversely, other caregivers reject the term because they consider their caring role a part of their existing role as parent, child, sibling or friend. Some caregivers have reported that the term interferes with the care recipient's efforts or status of independence. Moreover, stigma is commonly associated with the term, particularly for mental health caregivers, resulting in social isolation which can be an additional barrier to self-identification.

Recommendations

4. Regular national surveys to determine the prevalence of unpaid caregivers.
5. Increased public communication and awareness campaigns to improve public understanding about the role of caregivers.
6. A new National Carer Strategy include actions to reduce stigma associated with the caregiving role.

7. All jurisdictions implement training for frontline workers that enable them to identify caregivers and enable them to respond early to distress.
8. A new National Carer Strategy includes consultation with family and friends across all caregiving contexts about preferred language associated with their role and the use of the term 'carer'.

Caring for someone experiencing mental health concerns or suicidal distress

Caring for someone with a mental health condition such as depression or anxiety has unique challenges in comparison to those experienced in providing care for people with a physical illness, the elderly or end of life care. Emotional support is more commonly provided by mental health caregivers than physical illness caregivers, and practical tasks are less common in mental health caregiving. The role of a caregiver is driven by the needs of the care recipient. Chronic health conditions such as dementia and cancer have more determined caring needs as the trajectory of the illness is well defined. Comparatively, the needs of someone living with depression, for example, can change and fluctuate over time making it difficult for these caregivers to define their role, and therefore, more difficult to cope. Mental health caregiving is episodic and temporal, oscillating between periods of wellness and unwellness.

The intensity of caregiving and emotional strain increases for caregivers supporting someone who has attempted suicide or is experiencing suicidal distress. The intensity of the caregiving experience will vary depending on the chronicity and severity of the suicidal distress of the person being supported, the closeness of their relationship, other stressors being experienced by the caregiver, as well as the level of individual and structural supports available to the caregiver.

The 2022 Carer Wellbeing Survey indicated that caregivers of someone experiencing mental health concerns or suicidal distress continue to be significantly more likely to have very low levels of wellbeing and moderate to high levels of psychological distress than other Australians. Caregivers of someone with a mental illness are also more likely to be diagnosed with a mental illness themselves or experience suicidal distress.

Recommendations

9. A new National Carer Strategy is developed to align with the National Agreement on Mental Health and Suicide Prevention.
10. The Australian Government integrate lived experience knowledge into the development, delivery and evaluation of the new National Carer Strategy.
11. All jurisdictions include caregivers in the development of early distress interventions.
12. A new National Carer Strategy develops actions to integrate digital and face-to-face evidence-based support that address the unique factors of supporting someone experiencing mental health concerns or suicidal distress.

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