

Federal Budget Submission

August 2022

Labor government has opportunity to show leadership and care for Australia's 2.65 million unpaid carers in October 2022 budget





Introduction

This pre-Budget submission for the October 2022 budget, builds on the [Carers Australia 2022 Federal Election Platform](#) and May 2022-23 Budget submission, as the Federal Budget delivered on 28 May 2022 had no dedicated new funding provided to address carers¹ specific needs of unpaid carers and we continue to ask “who carers for carers?”.

Becoming a carer is often not a choice. The impacts of unpaid caring can be profound, particularly on their own health and wellbeing. Never has this been more evident than in the experience of carers during the COVID-19 pandemic, while being barely recognised or acknowledged for the extra caring responsibilities they undertook. When the pandemic is over, many carers’ lives will not return to ‘normal’ – they will continue to be isolated, financially disadvantaged, and unrecognised.

Carers simply cannot continue to plug the gap in supports for someone who has a disability, chronic or life-limiting illness, is frail aged, has a mental illness, or alcohol or other drug related condition without better and ongoing supports for their own health, wellbeing and financial security.

This October marks the 30th Anniversary of National Carers Week and this Budget provides an opportunity for the new Albanese Government to respond to carer issues which have been clearly and consistently represented to several governments through many reform processes since the [2009 House of Representatives Inquiry](#) without significant traction.

The [Carer Recognition Act 2010](#) (Commonwealth) aims to increase recognition and awareness of carers and acknowledge the valuable contribution they make to society. The cornerstone of the Act is the Statement for Australia’s Carers, setting out ten principles that articulate how carers should be treated and considered. It is with the Statement for Australia’s Carers in mind that Carers Australia provides the following Budget recommendations:

- Appoint a Commissioner for Carers a within Government (\$12 million over 4 years).
- Develop a National Carer Strategy endorsed by Australian Health Ministers (\$1.2 million/2 years).
- Commission a review of economic and financial security for carers by the Productivity Commission (\$5.2 million/3 years).
- Investigate the barriers to equitable access to respite care (\$2 million/2 years).
- Better support the mental health and wellbeing needs of carers (\$8.5 million/3 years).
- Provide independent individual advocacy for carers (\$25 million/3 years).

¹ Carers Australia uses the term ‘carer’ as defined by the [Commonwealth Carer Recognition Act 2010](#) (the Act), where it should not be used broadly and without context to describe a paid care worker, volunteer, foster carer or a family member or friend who is not a carer. The terms ‘informal carer’, ‘unpaid carer’ or ‘family and friend carer’ are also often used by organisations, government and the community to describe a carer. Carers Australia may use these terms to assist in providing context and to differentiate between other types of care provision.



Leadership within government

1. APPOINT A COMMISSIONER FOR CARERS

To lead a whole-of-government approach to carer recognition, inclusion and coordination and improve responsibility and accountability for carer support, to address diffusion of responsibility and perceptions that carer supports are a Department of Social Services only-role, or primarily focused on carers of people with a disability. The new Commissioner for Carers would be responsible for:

- Development, implementation and monitoring of a whole-of-government National Carer Strategy.
- Provide independent advice to Government on the needs and interests of carers, particularly those carers who are vulnerable, at risk or disadvantaged.
- Establish a high-level cross-departmental forum to coordinate carer legislation, policy, programs and services so they are effectively linked across Commonwealth portfolios.
- Review and strengthen the *Carer Recognition Act* into a rights-based Act, as the current Act is not binding on any other Act.
- Develop a Carer Impact Statement to inform future policies and decisions, and ensure carers are recognised as partners in care in social and health services.

\$12 million over 4 years

2. DEVELOP A NATIONAL CARER STRATEGY ENDORSED BY COAG

A new National Carer Strategy must involve supported community consultation and extensive engagement with stakeholders during planning, development and implementation to prepare for the 23% growth in demand for primary informal carers by 2030.² The Strategy should:

- Have a clear implementation plan that addresses carers' rights and needs, together with and separately from the people they care for, including secure employment, income and housing.
- Monitor implementation, outcome measures and the impact of state/territory jurisdiction-based carer strategies.
- Identify the data needed to monitor the social and economic impact of carer policies and programs.
- Consider the data gaps and limited research on carers and the resultant impact this has on the development of evidence-based health, aged-care, disability-support, and social policy and service planning.

\$1.2 million over 2 years

² Deloitte Access Economics (2020). 'The value of informal care in 2020' for Carers Australia [[accessed online](#)]

Why is this needed?

While the [Carer Recognition Act 2010](#) (Commonwealth) formally acknowledges the valuable social and economic contribution of carers in Australia, the last National Carers Strategy lapsed in 2014. Australia's 2.65 million carers are an essential part of our community and deserve a whole-of-government National Carer Strategy to deliver strategic direction and clear responsibilities across health and non-health portfolios for all people in care relationships.

Lack of recognition of the caring role and the impact of not being identified by services they interact with, in addition to limited appropriate and timely respite care and support are critical structural factors to our health, aged care, mental health, disability care and social service systems.

Thirteen years after the House of Representatives - Family, Community, Housing and Youth Committee launched the [Who Cares...?: Report on the inquiry into Better Support for Carers](#) (2009), carers are still not recognised, nor their rights and needs adequately embedded within reforms.

We are calling for carers' needs to enter the centre of policy consideration and for a National Strategy to form the foundation that can be built upon for long-term reforms and a sustainable change that will ultimately benefit carers, those they care for, government and society as a whole.



Economic and financial security

3. REVIEW OF ECONOMIC AND FINANCIAL SECURITY FOR CARERS BY PRODUCTIVITY COMMISSION

The Productivity Commission to undertake a broad review of economic and financial support for carers, which would underpin a coherent and flexible approach to address the barriers and long-term impacts on carers' financial and economic security as they maintain and thrive in their caring roles. Such a review should specifically include the following:

- Model the costs and benefits of providing retirement solutions such as a superannuation guarantee or carer pension credits to people who have had reduced employment opportunities due to providing continuous or long periods of care.
- Review the purpose, intent and adequacy of the Carer Payment and Carer Allowance and recommend ways to incentivise carers to participate in the workforce, education and training, without affecting carers who cannot work.
- Conduct a cost of caring and living analysis to examine implications for short-term and long-term financial security and economic outcomes across caring roles, with a particular focus on women, single carers, young carers and carers who identify as First Nations or LGBTIQ+.

\$5.2 million over 3 years

Why is this needed?

The right to participate in economic, social and community life is recognised under the [Carers Recognition Act 2010](#) which states carers “should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education”.

Carers in Australia experience considerably poorer employment outcomes, with a 52.2% employment to population ratio compared with 75.9% for people without caring responsibilities.³ The prospects for Australia’s 235,000 young carers are also poor, as more than 60% of young carers have not studied beyond high school, and on average are expected to receive income support for 43 years over their lifetime.⁴

Retaining connection to the workforce can constitute respite from caring, result in less social isolation and improve long-term employment opportunities, particularly important after years of dedicated caring. For employers, benefits include increased workforce diversity, retention of experienced staff and the loyalty of workers who appreciate the support they receive, as well as recruitment and retraining cost savings.

The [Caring Costs Us: The economic impact on lifetime income and retirement savings of informal carers – a report for Carers Australia](#) demonstrates a significant disparity in governments’ willingness to fund formal care services compared to investing in adequate financial assistance for carers to sustainably continue their caring roles and have security at retirement age. On average, the superannuation balance at age 67 of a person who becomes a primary carer is reduced by about \$17,700 for every year that they are a primary carer. Similarly, their lifetime earnings are reduced by \$39,600 for every year that they are a primary carer.

Removing barriers and supporting Australia’s 2.65 million carers to participate in flexible and appropriate paid work is pivotal to enabling their social, community and economic participation, and greater outcomes for community and governments as they maintain and thrive in their caring role.

Further, income support through the Carer Payment is less than 30% of the average weekly earnings, and the value of the Carer Allowance has significantly decreased since its introduction, where in 2021 it was just 6% of the average Australian Government Basic Care Subsidy payable in respect of a person in an approved Aged Care Home; and just 1.5% of the average amount payable in respect of a person living with disability in shared accommodation.



³ Australian Bureau of Statistics (2018). 2018 Survey of Disability, Ageing and Carers [\[accessed online\]](#)

⁴ Australian Government Department of Social Services (2017). ‘Try, Test and Learn Fund: Data Driven Job Opportunities for Young Carers Factsheet’ [\[accessed online\]](#).



Equitable access to respite options

4. INVESTIGATE BARRIERS TO ACCESSING RESPITE ACROSS SYSTEMS

For Government to appropriately support equitable access to respite, regardless of location, type of caring role, circumstance, service system accessed or relationship to funding or portfolio, a robust investigation into respite care needs to occur, which will also assist in future policy and reform decisions for a sustainable outcome. This should involve:

- A demand, needs and supply analysis for respite care, including across different categories of caring, such as aged care, disability, mental health, alcohol and drug services and palliative care programs, with attention to cultural appropriateness, availability, accessibility and affordability; responsiveness to the needs of both carer and person receiving respite care; and responsiveness to the needs of carers and people receiving care living in regional, rural and remote areas.

\$1.2 million over 2 years

- Journey mapping to better understand the characteristics of carers, the people receiving care and their broader social network that combine to contribute to situations with higher demand for emergency and planned respite.

\$800,000 over 2 years

Why is this needed?

The importance of respite has been highlighted in the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, the 2020 Productivity Commission Inquiry into Mental Health, and the 2021 Royal Commission into Aged Care Quality and Safety. The findings from these processes consistently note the cessation of funding for previous programs such as Mental Health Carer Respite Services, difficulty accessing respite (particularly community-based cottage respite) through the Carer Gateway, issues with aged care respite pathways (both community and residential) or palliative care-specific respite options, and very limited access to carer respite via the NDIS.

Equitable access and early referral to respite care, both planned and emergency, is critical to ensure sustainability of care relationships, and the health and wellbeing of carers. In many cases, lack of access to respite care can be the difference between maintaining the caring role or having no alternative but to seek other more costly government-subsidised care and accommodation options, cease or reduce employment, or risk further strain on carer and wider family relationships.

The cost to replace the care provided by unpaid family and friend carers with paid services within aged care and disability support alone would have cost the Australian economy [\\$77.9 billion](#) in 2020. That was before COVID and the impacts on the community it brought with it. Appropriately investing in respite care across systems, including aged care, disability, palliative care and mental health is a critical factor for government to prepare for the [23% growth in demand](#) for primary carers by 2030. This needs to be informed by the requested activities which must occur across portfolios and understand the nature of respite care demand and need throughout the diversity of caring.



Mental health and wellbeing

5. SPECIFIC MENTAL HEALTH AND WELLBEING ACTIVITIES THAT SUPPORT ALL CARERS AND ALSO REACH 'HIDDEN CARERS'

Caring can at the best of times be a rewarding yet demanding and socially isolating experience however carers have among the lowest levels of wellbeing of any group of Australians and are at a greater risk of negative physical and mental health effects. We recommend:

- Re-fund and extend the Carers Australia 'Caring through COVID' project, to engage and support the wellbeing needs and experiences of all carers during the ongoing pandemic and recovery, and supplement other COVID-19 mental health supports that are not carer-specific. Specific focus would be on the needs of carers of people with intellectual disabilities, people with autism spectrum disorder, and culturally and linguistically diverse carers.

\$1.6 million over three years

- Fund Carers Australia and the National Carer Network to co-design, evaluate and deliver locally identified and relevant mental health and wellbeing opportunities for carers across care relationships and settings. Specific focus would be put on activities that reach 'hidden carers' such as male carers, carers who identify as LGBTIQ+, culturally and linguistically diverse carers, grandparent carers and former carers, and be designed to complement and support referral into Carer Gateway services.

\$6.9 million over three years

Why is this needed?

The [2021 Carer Wellbeing Survey](#) revealed carers were two and a half times more likely to have low wellbeing than a person who does not have a caring role and carers were three times as likely as other Australians to regularly experience loneliness.

Carers Australia delivered the 'Caring through COVID' project in 2020-21, funded through the COVID-19 National Mental Health and Wellbeing Pandemic Response Plan. Independent evaluation determined a positive impact on carers' wellbeing, more people identifying themselves as a carer and high engagement increased social connectedness between participating carers and increased the number of carers accessing support pathways immediately after the program. Adding to the psychological distress experienced cumulatively since 2020 during COVID-19, carers are also providing more care, including more complex care as access to paid services reduced or in some cases ceased for long periods.

Specifically, carers of people with a mental illness often don't have the same visibility as carers of people in other circumstances, and this can be an additional obstacle to accessing recognition and support. Due to the fluctuating nature of mental illness, mental health carers manage a high level of unpredictability in their caring role in addition to a high level of emotional support, planning and behaviour management. There would be significant duplication in policy development, infrastructure and administration if carer specific supports related to mental health carers or the broader mental health of all carers, were separated without investigation of the unintended consequence of further fracturing carer supports.

The ability to localise and develop activities based on specific needs within communities is essential. Carers need support for their own mental health, where mental health services often focus on the needs of the person living with a mental illness or psychosocial disability without considering that the person providing care may also require mental health support, and in fact may also be a consumer of mental health services.

We highlight that all young carers are at increased risk of mental health issues, with approximately 235,000 young carers aged 11-25 years at risk of disengagement or who have disengaged from school or education opportunities due to caring responsibilities. Many young carers [report](#) a lack of sleep, ongoing stress and mental health issues which affects their motivation or ability to get up in the morning or go to school, and that their care responsibilities restrict their ability to achieve their potential, socialise with friends, participate in extra-curricular activities, and to build a sense of belonging.



6. INDEPENDENT INDIVIDUAL ADVOCACY FOR CARERS

Carers need increased advocacy and support, to enable their significant role as the hidden 'care coordinators' in negotiating and managing care across complex sectors and systems. Funding is required to establish and provide a rights-based independent and confidential advocacy service for individual carers, involving:

- Family and relationship services which better recognise the role of carers providing individual advocacy on behalf of, and with, people receiving care,
- Assisting carers to understand and exercise their rights,
- Raising and addressing issues relating to accessing and interaction with Commonwealth funded services for themselves and/or the person they are caring for, including health, aged care, disability, mental health and social services, noting carers may have multiple care relationships and interact with more than one sector,
- Assisting carers with sector navigation, including digital health literacy and access support, and
- Working in partnership with Carer Gateway Providers to improve cross sector and system navigation.

\$25 million over three years

Why is this needed?

Carers underpin the sustainability of health, aged care, mental health, and disability support systems and need advocacy for their own needs to continue this caring role effectively. Carers also play a significant role in coordinating, negotiating and managing care which may include care-related discussions with NDIS or aged care service providers, medical professionals, other family members and with the person receiving care about the arrangements for services. Carers need to understand legal and regulatory requirements around, for example, medications, decision making and competence, and legal factors influencing financial matters. In the context of the pandemic, factual information and advice

about COVID-19 is critical knowledge for carers. Carers also need knowledge and skills in self-care and support to plan for their own needs in a post-caring role.

Having access to support is associated with higher wellbeing, particularly for carers who are caring for one or more people with high assistance needs. Amongst those caring for people with high assistance needs in 2021, wellbeing was 10 to 11 points higher if the carer had access to support.⁵

It is a long-standing concern that carers continue to be largely mentioned or considered only in relation to "consumers, their families and carers" without recognition of their specific needs. The provision of evidence-based, culturally sensitive, targeted, accessible information and advocacy is needed to ensure that carers:

- Feel safe and confident in their ability to provide care and navigate complex systems,
- Have the appropriate knowledge to support themselves and the person they care for,
- Are informed of regulatory requirements specific to their situation, and
- Are able to raise issues related to carer-specific supports and services.

This would be similar to the supports available to older Australians who can access aged care advocacy, noting that at 20 June 2020 there were 1,175,889 people receiving Commonwealth funded aged care services across both residential and community programs⁶, compared to the 2.65 million carers that could benefit from independent advocacy.

While the [Carer Gateway](#) has a focus on tailoring supports, the aim is to give the carer time to balance the caring responsibilities and manage their own wellbeing so that they can continue to be there for those being cared for, not individual advocacy and navigation support.

Reform across settings and sectors including social services, while well intentioned, has potential to further fragment the provision of supports and services available to carers in all care relationships. Additional advocacy needs are also required for young carers aged under 25 years, and those carers from culturally and linguistically diverse backgrounds, those who identify as Aboriginal and Torres Strait Islander and who identify as lesbian, gay, bisexual, transgender, or intersex (LGBTIQ+).

⁵ Centre for Change Governance and National Centre for Social and Economic Modelling, University of Canberra (2021). 'Caring for others and yourself: The 2021 Carer Wellbeing Survey Full Report' on behalf of Carers Australia [[accessed online](#)].

⁶ AIHW GEN Aged Care Data [[accessed online](#)]

About Carers Australia

Carers Australia is the national peak body representing the diversity of the 2.65 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, alcohol or other drug related condition, terminal illness, or who are frail aged.

In collaboration with our members, the peak carer organisations in each state and territory, we collectively form the National Carer Network and are an established infrastructure that represent the views of carers at the national level.

Our vision is an Australia that values and supports all carers, where all carers should have the same rights, choices and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education. This includes carers:

- Who have their own care needs
- Who are in multiple care relationships
- Who have employment and/or education commitments
- Aged under 25 years (young carers)
- Aged over 65 years, including 'grandparent carers'
- From culturally and linguistically diverse backgrounds
- Who identify as Aboriginal and Torres Strait Islander
- Who identify as lesbian, gay, bisexual, transgender, intersex (LGBTIQ+)
- Who are living in rural and remote Australia; and
- Who are no longer in a caring role (former carers).

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