

# 2022-23 FEDERAL BUDGET SUBMISSION



## Time for carers to enter the centre of policy consideration

This pre-Budget submission complements the [Carers Australia 2022 Federal Election Platform](#) highlighting that 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 embedded within reforms. The Inquiry into Better Support for Carers (2009 Inquiry) provided a body of evidence clearly illustrating the profound physical, emotional and financial effects providing care has on carers and families. It called for carers, people receiving care, governments, and society to share the responsibility of providing care more equitably.

Carers underpin the sustainability of health, aged care, mental health, and disability support systems, by providing care to people with a chronic condition, terminal illness, mental illness, disability, drug or alcohol problem, or who are frail aged. In 2020, the estimated cost to replace this informal care for one year alone was \$77.9 billion.<sup>i</sup>

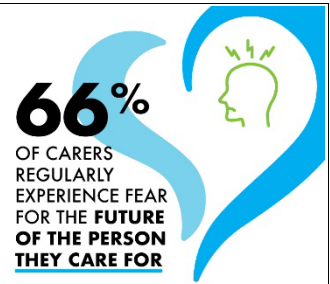
The *Carer Recognition Act 2010* (Commonwealth) aims to increase recognition and awareness of carers, and acknowledge the valuable contribution they make to society. The cornerstone of the Act is the Statement for Australia's Carers, setting out ten principles that articulate how carers should be treated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

These Budget asks provide an opportunity for Government to respond to carer issues and needs which have been clearly and consistently represented to several governments through many reform processes since the 2009 Inquiry. Additional support for this position – if needed – was outlined in the *National Health and Hospitals Reform Commission 2009 Report*, and more recently in the *2020 Productivity Commission Inquiry into Mental Health*, and *Royal Commissions into Aged Care Quality and Safety and Violence, Abuse, Neglect and Exploitation of People with Disability*.

Becoming a carer is often not a choice. The impacts on carers 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. Isolated, sheltering our most vulnerable Australians at home, carers have barely been recognised or acknowledged for the extra work they have done, unlike paid care workers. When the pandemic is over, many carers' lives will not change– they will continue to be isolated, financially disadvantaged, and unrecognised.

## APPOINT A COMMISSIONER FOR CARERS AND ESTABLISH AN OFFICE FOR CARERS WITHIN GOVERNMENT

The Carers Australia 2022 Federal Election Platform calls for Government to name a Minister for Carers, appoint a Commissioner for Carers and establish an Office for Carers to lead a whole-of-government approach to carer recognition, inclusion, and coordination.



The Commissioner for Carers would report to the Minister for Carers, and through the Office for Carers:

- Develop, implement and monitor a whole-of-government National Carer Strategy (refer below).
- 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 that 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.
- Improve responsibility and accountability for primary healthcare-related carer support within the Department of Health and relevant authorities, 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.

**\$12 million over 4 years**

## DEVELOP A NATIONAL CARER STRATEGY ENDORSED BY AUSTRALIAN HEALTH MINISTERS

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.

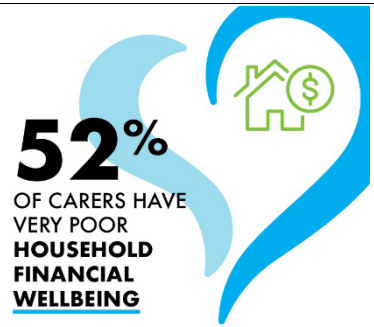
A new National Carer Strategy must involve supported community consultation and extensive engagement with stakeholders during planning, development and implementation to prepare for the 23% growth in demand for primary informal carers by 2030.<sup>ii</sup> The Strategy should:

- 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 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**

## 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.



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”.<sup>iii</sup>

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.<sup>iv</sup> 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.<sup>v</sup>

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. 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.

Such a review should specifically:

- 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 care and rely on the Carer Payment.
- 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 LGBTIQ+.
- Provide tangible, actionable solutions to address barriers identified through this analysis.

**\$5.2 million over 3 years**

## INVESTIGATE BARRIERS TO EQUITABLE ACCESS TO RESPITE CARE

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.

An infographic consisting of a large blue speech bubble shape. Inside the bubble, there is a green icon of a hand holding a heart. To the left of the bubble, the text reads: "ONLY 19% OF CARERS CAN EASILY ORGANISE FAMILY OR FRIEND SUPPORT".

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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 *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 National Disability Insurance Scheme.

For Government to appropriately support equitable access to respite, regardless of location, type of caring role or circumstance, or service system accessed or relationship to funding or portfolio, the following must be funded:

- 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**

## SUPPORT THE MENTAL HEALTH AND WELLBEING NEEDS OF CARERS

Caring can at the best of times be a rewarding yet demanding and socially isolating experience. Carers have among the lowest levels of wellbeing of any group of Australians, even before the impact of COVID-19.

Australia's carers in 2021 were two and a half times more likely to have low wellbeing than a person who does not have a caring role, and the average psychological distress score for carers aged 30 to 44 was 6.7 points higher than that of the general population.<sup>vi</sup> During the pandemic some carers faced the additional challenge of needing to reduce their economic and social participation and maintain more restricted isolation practices due to the vulnerability of the person they care for. This has further impacted on carer mental health and wellbeing, where 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.

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The project focused on mental health and wellbeing supports to enable carers to connect with other carers, assess and monitor their own mental health, and engage with online resources which promoted self-care and wellbeing. Between May and September 2021 over 4,300 carers participated in 36 online mindfulness sessions and there were 2,188 listeners to a carer-specific podcast series. Independent evaluation of the project determined a positive impact on carers' wellbeing and more people identifying themselves as a carer to access supports. High engagement with the program increased social connectedness between participating carers and increased the number of carers accessing support pathways immediately after the program.

- Continue to fund, and extend, the '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 and 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**

## INDEPENDENT INDIVIDUAL ADVOCACY FOR CARERS

**Carers need increased advocacy and support, to enable their significant role as the hidden 'care coordinators' negotiating and managing care across complex sectors and systems.**

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 wellbeing was 10 to 11 points higher if the carer had access to support.<sup>vii</sup>



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.
- Assist carers to understand and exercise their rights.
- Raise and address issues relating to accessing and interacting 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.
- Assist carers with sector navigation, including digital health literacy and access support.
- Work in partnership with Carer Gateway Providers to improve cross sector and system navigation issues.

**\$25 million over three years**

## 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, drug or alcohol problem, 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).

Carers Australia acknowledges Aboriginal and/or Torres Strait Islander peoples and communities as the traditional custodians of the land we work on and pay our respects to Elders past, present and emerging. As an inclusive organisation we celebrate people of all backgrounds, genders, sexualities, cultures, bodies and abilities.

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<sup>i</sup> Deloitte Access Economics (2020). 'The value of informal care in 2020' for Carers Australia [\[accessed online\]](#).

<sup>ii</sup> *Ibid*

<sup>iii</sup> *The Carer Recognition Act (Cth) 2010*. 'The Statement for Australia's Carers' Principle 9 [\[accessed online\]](#).

<sup>iv</sup> Australian Bureau of Statistics (2018). 2018 Survey of Disability, Ageing and Carers [\[accessed online\]](#)

<sup>v</sup> Australian Government Department of Social Services (2017). 'Try, Test and Learn Fund: Data Driven Job Opportunities for Young Carers Factsheet' [\[accessed online\]](#).

<sup>vi</sup> 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 [\[accessed online\]](#).

<sup>vii</sup> *Ibid*